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The Lived Experiences of Persons Dependent on Hemodialysis

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THE LIVED EXPERIENCES OF PERSONS DEPENDENT ON HEMODIALYSIS

By

Molly A. Kidner

A THESIS

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ABSTRACT

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End Stage Renal Disease (ESRD) affects almost 300,000 people in the United States. The growth rate is estimated at six to seven percent per year. Of these, over 182,000 chose hemodialysis as the treatment regime to sustain their lives. Qualitative research is relatively absent specific to this population.

The purpose of this phenomenological study was to discover the lived experiences of persons dependent on hemodialysis. Four self-identified persons dependent on hemodialysis were asked to describe their experiences of being a person dependent on hemodialysis. The verbal descriptions were tape-recorded and transcribed verbatim. These descriptions were analyzed for meaning using the Giorgi method. Three focal meanings emerged: 1) starting dialysis, 2) living with dialysis, and 3) acceptance and outlook on the future. Nursing can utilize the information from this research to develop strategies to better address issues specific to this population.

DEDICATION

This thesis is dedicated with my heartfelt thanks and deepest love to my husband, Brian Kidner. He has provided encouragement, support, and been my unwavering strength throughout my educational endeavors.

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I wish to express my sincere gratitude to my committee members, Dr. Barry Kram, Dr. Phyllis Gendler, and my committee chair-person, Dr. Lorraine Rodrigues-Fisher, who has graciously shared the benefits of her considerable experience involving phenomenological research. I also wish to thank the people who welcomed me into their homes and lives to share their personal experiences.

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CHAPTER I

Introduction

End Stage Renal Disease (ESRD) is a condition in which an individual's renal function becomes unable to sustain life. It is characterized by a progressive and irreversible decline in glomerular filtration rate, and is caused by a large number of diseases (Bennett & Plum, 1996). The U.S. Renal Database System (USRDS 1998 Annual Data Report) reports that there are 283,932 patients being treated for ESRD, and 73,091 new patients started therapy that year alone in the United States. The 1996 incidence rate is estimated at 268 per million and the prevalence rate at 1,041 per million. The growth rate of new ESRD cases is estimated at six to seven percent per year (USRDS 1998 Annual Data Report).

Although ESRD is rarely noted as the cause of death, ESRD patients experience exceptionally higher death rates as compared to the U.S. population as a whole. Expected lifetimes of ESRD patients are between 17 and 39 percent of those for the age-sex-race matched U.S. population. Causes of death are almost always related to comorbid conditions, with cardiac events as the leading cause. Between 1994 and 1996, approximately 100,000 ESRD patients died (USRDS 1998 Annual Data Report).

Over 250,000 ESRD patients are currently alive in the United States as a result of ESRD therapy, compared to 11,000 in 1973. Treatment options for ESRD patients include several different modalities: renal transplantation from living or cadaveric donors, hemodialysis, and peritoneal dialysis. According to the U.S. Renal Database System, over 182,300 patients chose hemodialysis as their preferred treatment option (USRDS 1998 Annual Data Report).

Hemodialysis is a process whereby toxins and excess fluid are removed via extracorporeal circulation of blood through a dialyzer, also referred to as an artificial kidney. Treatments are commonly scheduled three times weekly and last three to five

hours. A vascular access is required, using an arterio-venous fistula, vascular graft, or indwelling vascular catheter. The treatment is performed predominantly as “center dialysis” in a hospital-based or freestanding dialysis unit (USRDS 1998 Annual Report).

Hemodialysis patients must make many alterations in their lifestyles in order to maintain a reasonable level of wellness. Strict adherence to the treatment regimen is necessary, as are immediate and severe dietary and fluid restrictions. A vascular access is needed, and the hemodialysis patient must undergo procedures to create and maintain these lifelines. Becoming familiar with the insurance/Medicare/Medicaid system is a task that must also be accomplished. In many cases, the hemodialysis patient must find new and creative ways to financially sustain themselves and their families if they are no longer able to maintain employment. The psycho-social issues a hemodialysis patient must contend with are immense.

Purpose

The purpose of this study was to explore, examine, and describe the lived experiences of persons dependent upon hemodialysis therapy for survival, and describe the underlying themes through self-reflection on their thoughts, feelings, and perceptions related to hemodialysis and its impact on their lives. The Husserelian Phenomenological method was utilized in this study, which consists of four phases: bracketing, intuiting, analyzing, and describing.

Research Question

This study explored, examined and describes: What are the lived experiences of persons dependent upon hemodialysis for survival? The phenomenological method was selected to gather information relative to this inquiry.

Research Design

Husserelian Phenomenology is the method of choice to explore, examine, and describe the lived experiences of people dependent on hemodialysis. Husserl, the “father of phenomenology”, believed that the goal of philosophy was to describe the data of

consciousness without bias or prejudice, ignoring all metaphysical and scientific theories in order to accurately describe and analyze the data gathered by human senses and the mind (Marvin & Sikernitsky, 1997). Husserl's students summarized phenomenology as the study of "the things themselves" (Wyatt, 1997). Reviewing the literature is postponed so as to minimize influencing the researcher. Phenomenology is an approach to thinking about what the life experiences of people are like. The researcher asks the question: What is the essence of this phenomenon as experienced by these people (Polit & Hungler, 1995)?

Researcher's Perspective

The researcher's perspective about the phenomenon of the lived experiences of persons dependent on hemodialysis is required when using the phenomenological method. This research method is conducive to the development of nursing interventions (as well as interventions from other disciplines) and formulation of more accurate conceptions of this patient population. The perspective of the researcher was held in abeyance during this study.

A great deal of medical research has been conducted on this patient population, but nursing research is noticeably absent. The greatest concentration of research effort is centered on the physiological aspects of hemodialysis patient care, while the psychological, social, cognitive, and spiritual aspects are largely ignored. During this researcher's professional nursing career and experience with hemodialysis patients, numerous issues have suggested that the physiological component of patients with renal failure is not, or certainly is not always, the primary problem as defined by the patient.

There appears to be a clear need to examine the hemodialysis patient on a more holistic level. The most effective way to achieve this is through qualitative, phenomenological research.

CHAPTER II

Literature Review

Introduction

When utilizing the phenomenological research method, literature review is postponed until after the data are collected. This is an additional tactic to refrain from influencing the researcher and facilitate maintaining an unbiased perspective. This technique is known as “bracketing” information. Bracketing is part of the process of recovering original awareness, called “reduction” in phenomenology to aid in this process (Oiler, 1993.).

Preserving validity of the data is of utmost concern in phenomenology. Oiler (1982) suggests that the test of validity relates to whether the findings are recognized to be true by those who had the experience. Validity in phenomenological research is grounded in “the uniqueness of each lived experience of the phenomenon, while permitting and understanding of the meaning of the phenomena itself” (Bononis, 1989).

Literature review related to the lived experiences of persons dependent on hemodialysis was reviewed after data collection and analysis, and is compared and contrasted in a subsequent chapter. Literature review related to phenomenological research and Husserlian Phenomenology will be discussed in this chapter, as well as further discussion of the research methodologies.

Qualitative Research

Qualitative research identifies the characteristics and the significance of human experiences as described by co-participants and interpreted by the researcher at various levels of abstraction. In qualitative research the researcher’s interpretations are intersubjective, that is, given the researcher’s frame of reference, another person can come to a similar interpretation. Qualitative data are processed through the creative abstractions of the researcher as the co-participants’ descriptions are studied to uncover the meaning of human experiences (Parse, et al, 1985).

The qualitative approach offers the researcher the opportunity to study the emergence of patterns in the whole configuration of Man's lived experiences. It is an approach in which the researcher explicitly participates in uncovering the meaning of these experiences as humanly lived. In qualitative research, descriptions from co-participant observation, structured and unstructured interviews, and written and oral retrospective accounts are studied for themes (Parse, et al., 1986).

There are several different research methods that are considered qualitative, including: grounded theory, phenomenology, ethnomethodology, ethnonursing, feminist methods, historical and philosophical inquiry (Sandelowski, 1986). Each of these methods incorporates a different focus and style.

Grounded theory is frequently used in connection with a certain approach to analyzing qualitative data. This method was developed by two sociologists, Glaser and Strauss (1967). It involves the generation of theory on the basis of comparative analysis between or among groups within a substantive area, using methods of field research for data collection. The term grounded theory refers to the fact that a theorization does not spring from the investigator's preconceived hypotheses about a social situation but rather is discovered by being grounded in the data (Polit & Hungler, 1995).

Ethnomethodology is a branch of human inquiry, associated with sociology, that focuses on the way in which people make sense of their everyday activities and come to behave in socially acceptable ways (Polit & Hungler, 1995). Ethnonursing, developed by Madeleine Leininger, is a study of human cultures, with a focus on a group's beliefs and practices relating to nursing care and related health behaviors (Fawcett, 1993).

Historical research is the systematic collection and evaluation of data relating to past occurrences. Generally, historical research is undertaken to answer questions concerning causes, effects, or trends relating to past events that may shed light on present behaviors or practices (Polit & Hungler, 1995).

The aim of feminist research is to promote social change and involves participation of the researcher (Sandelowski, 1986). Feminist ideology values all human experiences, endorses women, challenges patriarchal systems, and focuses on creating respect for all others (Chinn & Kramer, 1992).

Phenomenological research is historically based on the work of German philosopher Edmund Husserl (1859-1938). In simplistic terms, it is an approach to thinking about what the life experiences of people are like. The phenomenological researcher asks the question: What is the essence of this phenomenon as experienced by these people? The phenomenologist assumes there is an essence that can be understood, in much the same way that the ethnographer assumes that a culture exists. The focus of phenomenological inquiry is what people experience regarding some phenomena and how they interpret those experiences (Polit & Hungler, 1995).

Oiler (1982) asserts that phenomenology is a philosophy, an approach, and a method, the aim of which is a better understanding of patients' experiences. She maintains that this methodology speaks to nurses who have a reverence for patients' experiences, and it is precisely this reverence that aligns nursing concerns with phenomenology (Koch, 1995).

Qualitative methods have been criticized because they do not provide explicit rules for achieving reliability, validity, and objectivity. It has been argued that the use of qualitative methods can offer a nursing-appropriate methodology that fits a unique phenomenon of discernment such as person, environment, health, and nursing (Swanson-Kaufman, 1986). It is not always necessary or appropriate to adhere to accepted assumptions and rules of the natural sciences. Rather, nurses should generate methods that allow study of people as holistic individuals who are in a process of becoming (Drew, 1993). Based on these concepts and beliefs, the phenomenological methodology was selected as ideal for exploring the lived experiences of hemodialysis-dependent people.

Phenomenological Research

Husserl's phenomenology has come to mean the study of phenomena as they appear through the consciousness. Husserl is quoted as saying "Everything which is and has reality for me, that is, for man, exists only in my own consciousness" (Wyatt, 1995). Central to Husserl's approach is the fundamental recognition of experience as the ultimate ground and meaning of knowledge. The hallmark of genuine phenomenological inquiry is that its task is a "matter of describing" (Koch, 1995). Thus the inquirer using Husserlian phenomenology always asks about the meaning of human experience. According to Husserl, the "lived experience" is not readily accessible because it constitutes what is taken for granted, or those things which are common sense. The task, then, is to return to the taken-for-granted experiences and reexamine these, bringing to light the ultimate structures of the consciousness (essences) and to evaluate critically the role these structures play in determining the sense of it all (Koch, 1995).

One of Husserl's directives to phenomenology was that it should be descriptive psychology, which would "return things to themselves" and to the essences that constitute the consciousness and perceptions of the human world. Thus, phenomenological research means presenting the world as it is manipulated in the mind, as these manipulations permit the external world to be brought into internal consciousness by cognitive processes (Koch, 1995).

The people who live the experience are the sources for data collection in phenomenological studies, but the way in which experiences are presented to others must be established (Oiler, 1982). What people say or write about their experiences is important, as are their actions, gestures, and expressions. The design of the research needs to find ways of collecting descriptions whilst preserving the spontaneity of the subjects' lived experiences (Jasper, 1994). The techniques selected are limited only by imagination and ethics (Oiler, 1982).

This study utilized the Husserlian phenomenological approach to explore, examine, and describe the lived experiences of persons dependent on hemodialysis for survival, and to identify the feelings, thoughts, and perceptions of this population. The study variables were limited to the individuals' personal experiences and perception, and common themes were sought.

The research design for this qualitative study consisted of four phases of Husserlian phenomenological research: bracketing, intuiting, analysis, and describing. The researcher bracketed out explanations regarding the phenomenon of the lived experiences of persons dependent on hemodialysis. This minimized researcher biases and facilitated the researcher's ability to view the phenomenon openly, without preconceived ideas or conceptions. The research's description of the lived experiences of persons depend on hemodialysis is from data real situations as described by the co-participants.

Significance for Nursing

The scientific method is far too narrow, reductionistic, and controlled to let one know human beings in their totality and help them in times of wellness and illness. Because of this, a cultural movement is slowly taken place in shifting the focus away from the qualitative and other alternative research methods (Leininger, 1985). Capera (1983) is a vocal advocate of the trend in shifting methodological frameworks. She states:

Scientific theories can never provide a complete and definitive description of reality. They will always be approximations to the true nature of things. To put it bluntly, scientist do not deal with the truth; they deal with limited and approximate descriptions of reality....Scientists will not need to be reluctant to adopt a holistic framework, as they often are today, for fear of being unscientific. Modern physics can show them that

such a framework is not only scientific but is in agreement with the most advanced scientific theories of physical reality. (Capera, 1983).

This cultural movement could well revolutionize nursing knowledge and practice and provide new directions in nursing. On one hand, the scientific method had yielded only limited substantive knowledge about the nature of nursing. Qualitative research understanding human groups and their care and health needs. Qualitative methods give new hope to the discovery of extremely covert, subtle, and objective realities and truths about the meaning and expressions of health in individuals both within health institutions and in community settings (Leininger, 1985).

Phenomenological methodology emphasizes the importance of individual lives and experiences. A well-constructed, credible qualitative research study will promote the art and science of nursing. Phenomenological inquiry regarding the lived experiences of hemodialysis patients is a step in the identification of the shared meanings and unique experiences of these people and will promote identification of the unique needs of this population.

CHAPTER III

Methodology

Introduction

For the study of the lived experiences of persons dependent on hemodialysis, data was gathered primarily by use of unstructured personal interview to capture the experience. This was accomplished by asking the co-participants to describe the phenomenon as fully and deeply as possible, until they had no more to say (Jasper, 1994). The researcher utilized interviewing techniques including the use of reflection, clarification, requests for examples and description, and the conveyance of interest through listening techniques to assist in minimizing data contamination (Jasper, 1994).

If the co-participant desired to have another person present during the interview, this was permitted. This individual did not prompt the co-participant or contribute to the interview and such presence was solely for the support of the co-participant. One of the four co-participants did have a support person present for a portion of the interview, and the support person did not contribute to the interview in any way. This chapter will describe the setting, sample population, method of data collection and analysis of data.

Setting

Co-participants were recruited from one outpatient hemodialysis unit in the Midwestern United States. Interviews took place in the co-participants' residences to protect privacy and facilitate full disclosure in the interview. Interviews were conducted on a one-to-one basis by a singular interviewer (the researcher). The co-participant was asked to describe, as deeply and fully as possible, the experience of hemodialysis. It was anticipated that this would include current and past experiences and implications in the lives of the co-participants.

Sample

For this study of the lived experiences of hemodialysis patients, the co-participants were selected from one Midwestern outpatient hemodialysis clinic. The

sampling method was a purposive sample. A poster outlining the purpose of the study and request for participation was on display in the hemodialysis clinic waiting area (Appendix A). Respondent cards were available for those potential co-participants to submit to the Clinical Manager (Appendix B). Of those who respond to the request for participation, the Clinical Manager selected four who best met the criteria specified. The Clinical Manager attempted to provide demographic diversity in her selections, including Caucasian and African-American, elderly and young adult, male and female (this clinic has no Hispanic or Asian people receiving therapy at this time). The criteria used to select or eliminate co-Participants will now be addressed.

Criteria for admission:

1. Will be agreeable to participation.
2. Is legally competent.
3. Will be free of influencing (sedatives, hypnotics) medications.
4. Has been receiving hemodialysis therapy for six months or longer.
5. Believe they can tolerate a lengthy interview.
6. Is fluent in English.
7. Is free of hearing impairments.

Criteria for exclusion:

1. Has an appointed legal guardian.
2. Experiences impaired judgment, delusions, seizures, hypoglycemic reactions, or other conditions known to impair cognition either at the time of consent for participation or during the interview process.
3. Has known short- or long-term memory impairment.
4. Has less than six months experience with hemodialysis therapy.
5. Verbalize doubt they can converse for one hour without becoming fatigued.
6. Has a strong accent or speech impediment.

A manageable sample size of four co-participants assisted the researcher in studying the phenomenon intensively rather than extensively. According to Polit & Hungler (1995), small samples are adequate to capture a full range of themes emerging in relation to the phenomenon of interest, especially if theoretical sampling has been used judiciously. The researcher facilitated selection of co-participants from a variety of demographic backgrounds to capture a wide range of experiences.

Protection of Human Rights

Approval for this study was obtained from the Institutional Review Board of Grand Valley State University (Appendix C). The research question and the purpose of this study was discussed with each co-participant. The investigator explained the amount of involvement and required time commitment from the co-participant. The investigator obtained written consent from the co-participants and answered any questions concerning the study. Co-participants received a copy of their signed consent form. The original consent was retained by the investigator in a locked file accessible only to the investigator. The co-participants were informed she or he had the option of withdrawal from the study at any time. None of the selected co-participants elected to withdraw throughout the interview processes.

Possible risks and discomforts of the study were identified. There was no physical risk in this non-invasive research. Some emotional discomfort may have occurred when reflecting on past experiences. Assurances were made to maintain anonymity and confidentiality. The researcher took steps to minimize and reduce these identified risks:

In a study involving the interviewing of hemodialysis patients:

Risk: The co-participant may become unduly tired.

Interventions to reduce risk: The researcher will discontinue the interview upon signs that the co-participant is tired or at the co-participant's request.

Risk: The co-participant may experience an acute medical difficulty (hypotension, hypoglycemia, cardiac event, etc.).

Methods to reduce risk: The researcher will terminate the interview at the slightest suspicion of medical difficulties. The researcher will assess the co-participant, notify family members and/or community resources, and assist the co-participant in seeking appropriate medical treatment.

Risk: The co-participant may become frustrated, angry, or hostile if discussing sensitive issues.

Methods to reduce risk: The researcher will discontinue the interview if there is a perceived threat of violence, verbal abuse, inappropriate behavior, or at the co-participant's request. The researcher will offer to assist in referring the co-participant to the social worker who sees him or her regularly at the hemodialysis clinic. The researcher will reiterate the option to withdraw from the study at any time, or offer to reschedule the remainder of the interview at the co-participant's convenience. If the co-participant opts to withdraw from the study, another co-participant will be selected by the clinical manager of the clinic.

None if the identified potential risks or distresses occurred with any of the co-participants. It was therefore unnecessary to implement any of the proposed interventions.

Potential co-participants were given information as to the purpose and nature of the study, the time commitment and involvement if the co-participants was explained, and the option to withdraw at any time was affirmed. Confidentiality and anonymity was assured. All interviews were tape-recorded, transcribed verbatim, and were destroyed by the researcher after assessing accuracy of transcription. Transcription records were

destroyed via paper shredder after completion of data analysis. Co-participants were informed that if descriptions are published, no names or identifying characteristics will be associated with the data (Parse, Coyne, & Smith, 1985). The point of phenomenological research is to “borrow” other peoples’ experiences in order to better come to an understanding of the deeper meaning or significance of an aspect of human experience in the context of the whole human experience (Ray, 1991). The ethics of informed consent must apply (see Appendix D).

Data Collection and Analysis of Data

Data for the qualitative study of experiences of hemodialysis patients was collected using observation, listening, and interviewing techniques. The Giorgi (1975) method of data collection and analysis was used, which incorporates the processes of intuiting and dwelling with the data, analysis, and then describing the phenomenon. Strict adherence to contemplative dwelling with the data was maintained. Contemplative dwelling is the undistracted reading and re-reading of the descriptions with the intent to uncover the meaning of the lived experience for the subjects. This frees the researcher to be open to both the tacit and explicit messages in the data (Parse, et. al., 1985).

Using these concepts, the researcher utilized the following steps in this study:

1. The researcher read the entire transcript of each description in order to obtain essence of the whole.
2. The researcher re-read each transcript and identified central meanings.
3. Developing themes were identified from each description.
4. The themes were compared between co-participants.
5. The researcher reflected on the themes, and transformed the meanings of verbatim into concepts.
6. The researcher synthesized and integrated the identified focal meanings into a structural description of the phenomenon.

The data collection was compiled by the investigator, a registered nurse and a graduate student in the Master of Science in Nursing program at Grand Valley State University. The data collection was scheduled to occur over a two to three week period dependent upon co-participant availability. Each co-participant was asked to describe his or her experience as a person dependent upon hemodialysis. All interviews were audio-tape recorded. Instructions were given to each co-participant one week prior to the interview, so that they had time to formulate their responses. The instructions to each co-participant were:

Describe in detail your experience as a person dependent upon hemodialysis.

Please share all the thoughts and feelings you are able to recall until you have no more to say about your experience.

The interview was considered complete when the co-participants felt they had completely exhausted their description of their lived experience. Upon completion of the interview, the co-participant was informed that he or she would be contacted by telephone to determine if the essence of his or her lived experience had been captured by the interviewer. At that time, the co-participant were given the opportunity to question, clarify, or add to any of the information.

The researcher listened to the tape recorded interviews immediately following each interview, then again at later dates. The interviews were transcribed verbatim by the researcher and were checked for accuracy before the researcher analyzed them. The co-participants were identified by numbers derived from: order of interview (01 - 04), gender (01 = male, 02 = female), race (01 = Caucasian, 02 = African-American), and age (age in years), so that a sample co-participant number appears as (01020269).

Validity

Validity in phenomenological researcher is grounded in the “uniqueness of each lived experience of the phenomenon, while permitting an understanding of the meaning

of the phenomena itself” (Banonis, 1989). Validity is generally taken to mean that the research design tests that it sets out to test (Jasper, 1994). It is suggested that the test of validity in this type of research relates to whether the findings are recognized to be true by those who have had the experience (Oiler, 1982).

The purpose of phenomenology, in its mission to identify the “essence” of an experience, differs greatly from that of scientific methods which generate theories of explanative and predictive value. Thus, the question of generalizability in phenomenology is inappropriate in that the researcher does not intend to produce a theory of general application at the onset (Jasper, 1994). The purpose is instead to generate concepts and theories which can then be tested using other methods (Jasper, 1994).

Within the qualitative discourse of nursing, authors use various terminology in reference to validity. Some authors speak of error and accuracy, others of reliability, bias control, bias reduction, or rigor in describing their methodological aims and techniques (Kahn, 1993). The goal of the research, however is to describe the essence of the phenomena. In order to accomplish this, the researcher must recognize and identify factors which could influence a false interpretation of the data.

The test of validity in qualitative, phenomenological research is that the co-participants will recognize the findings to be true. The co-participants were contacted by telephone following data analysis by the researcher, and questioned as to whether the findings reflected the true meanings of their experiences. Since the agreed, validity has been achieved.

CHAPTER IV

Data Analysis

Through the processes of dwelling with and analyzing the data, three focal meanings became evident from the co-participants' descriptions of the lived experience of being a person dependent on hemodialysis. Identified themes in each focal meaning are included, followed by samples of the co-participants' actual descriptions.

Focal Meaning One

Starting Dialysis

Theme One: Initial Reaction

- As to dialysis, I was really concerned about it. Because of the entrapment. Your life is really different, and that was my major concern. I didn't want to be strapped to one of those machines. We'd been traveling a lot and just didn't want to get hung up. And I fought it and fought it, for years, from 1994 to 1996.
- I say, they probably told me two years ahead of time that I was gonna lose my kidney function, it just kept getting worse and worse. So, when two years got there, I guess I was kinda immune to it by then.
- I had so much guilt at knowing I should have taken better care of myself, and I realized it was more or less my own fault. I was very, very, very devastated, very devastated because I didn't have any medical insurance, and, um, it was just like, I would always use the phrase that I'd been "laid off from life".

Theme Two: The Cause

- I graduated in '82, and I worked for two years when I got the butterfly, and my skin was turning purple. I just hurt all over. And right after that they found out that I had lupus. And I was in the hospital a lot with lupus. My kidneys failed in, I think it was '93. I think it was '93 they failed, and the lupus just, well, went down. I've only been in the hospital because of the kidneys since then. That's what did it, the lupus.
- And she explained it to me that there's antibiotics that are dangerous as far as your kidneys are concerned. And she explained to me that some of them would wipe them out. So that's where I got the insight, I mean, I'm pretty damn sure it was the antibiotics. Cause I had nothing else, see?
- You know, it's something that I did and I know that there's nothing that will make me believe any differently. That if I had taken better care of myself, that I may have been on dialysis, but not as soon. Even today I realize that if you can keep your blood sugar close to normal as possible, then you don't have to worry so much about this stuff, you know, your eyes, and your feet, your kidneys, heart, all those things.
- Course, if I'd have taken better care of myself, like anything's else, like I'd say, okay, I'm on blood pressure medication, but I'll have me a few drinks, I don't think that helps anything when you're on blood pressure medication. They didn't say that was the problem, but they said it was all them years I was on medication, just got the best of my kidneys.

Theme Three: Socio-Economic Impact

- Then I had to work out how I was going to, what I was going to do about keeping my job. It took a lot of hassle, you know, to do it. But I got to keep my job.
- I started in '94. doing hemo. I was still working at that time, when they told me I had to go on kidney dialysis I went back to my company and I asked them if I could still work, you know, I wouldn't be able to work overtime. And they got with the union and they said no, they'd have to retire me.
- And I wasn't bringing in any money, so there was so much I couldn't do, and I would get so depressed about the medical bills.

Theme Four: Fear

- And my wife, well, it tears her up. She thinks I'm going to die on her. Every time I get out of dialysis I give her a call right away.
- Hemodialysis ain't the best thing in the world, but it's better than dying.
I just take one day at a time. I don't think about the next day.
- Cause I don't want somebody to bump me. Start bleeding or something. I don't know. I just worry about it. Fragile, yeah, that's a good way to put it. I'm kinda scared of people, too, you know? Some people can be cruel. I feel safe right here. But usually I don't like going too far from the house. I feel safe here, I guess.
- If I go there, I get life. If I don't, I die.

Focal Meaning Two

Living With Hemodialysis

Theme One: The Needles

- And the other thing I did was develop my “chicken juice”. I mean, that helps a lot. A lot of those people are scared shitless of those needles. Those needles, man, I mean I’ve seen people scream and yell, I mean, it’s traumatic. They just go crazy!
- Well, the worst thing is they have to poke needles in you. Big needles. One going one way, the other going the other way. In your arm. That’s not a very good, um, situation.
- You know, in the beginning, I always thought I could not stand it, could not stand it, those needles. But it hasn’t been so bad. It’s painful sometimes, I sometimes had to have four needles, three on one side, one here.
- That was one of the reasons I didn’t want hemo. I just didn’t think I could stand that big sewing-machine needle!

Theme Two: Influence of Support System

- She’s never been in to see the unit or the machines. I’ve tried to get her to come in, like the time I was in that new unit. There wasn’t anybody there except myself, but she wouldn’t do it. She was invited to tour the unit on a couple occasions. I guess we didn’t get to the point where we were going to drag her in.
- Well, my wife is pretty level-headed. They took her down there and explained other what it was all about and what was going to happen, and she just accepted it, you know? But it could disrupt, I

guess, if she was a tense woman. I suppose it would bother her a lot.

- When I came down with lupus in '84 all my friends just went away. I don't have any friends now. They went away like it was contagious, so I just hang out with my family. It was hard, cause I had a lot of friends.
- And she said that, you know, and I said, "You know, I'm one of Jehovah's Witnesses, and I think Jehovah has given me a blessing, giving me hemo. And he gives nothing but good gifts". You know how I feel, I feel very, very thankful that I have my religion, because my religion is what helped me. Because the friends in the Kingdom Hall where we go, they was always just so good to me. Just, just good, and that helped me. My family has always been there, and that helped me.
- So, Mom's never been sick, and we can just ignore it. No, no. She's unh-unh, no. I have one daughter, she cannot, she does not face anything. So they kind of push things away. But you know, I do think it bothered them that Mom's not Mom. Cause I've always been the strong one, always the one to make the decisions, say you can or you can't.

Theme Three: Impact of Dialysis Center Staff

- And what was fun was, the nurse I had was from the kidney center. Barbie, I call her Barbie 1. You know, we had so many Barbs at one time. Yeah, Barbie1, Barbie2, and Barbie 3 was at the desk. Barbie 2 is still over there with you. Barbie 1 is working on 2nd

floor. It was great to see her. She use to give me all kinds of special care, you know?

- And Friday nights I worry because everyone is in a hurry to get out of there. I have to prompt some of the people about getting my medication and when I'm supposed to have it. And some of the transient people that are in there are somewhat careless sometimes. There's some techs, you know, they just want you to get in, sit down, shut up, and let them do their thing. You get that feeling.
- If I was gonna complain, I guess really one of the biggies is I don't believe they train the people that's poking the needles in ya enough.
- As far as the center down there, I think they're the staff is overworked for as many patients as they got. That's the way I feel. You get good help and pretty soon they move on to someplace else and you got to hire and train all over again.
And personally I think we need at least one more doctor in there, our doctors are so spread out.
- I think what helps at dialysis is the nurses: they come and talk to you. They treat you like you're friends. Like Dave, when I walk in there he says "Hey, (nickname)!" I mean, I feel like they're my friends. Some nurses are kinda, they, um, I think they hold back so they don't get close to us. Cause then when one passes away, it's hard on you guy's, isn't it? But that helps alot. We talk about their kids, what we did over the weekend.
I guess they are my friends, the nurses.
- Sometimes you get some that are very understanding, and they do

realize that it isn't easy for you. And then you got some that doesn't have the compassion, and I find mostly it's the techs, I think mostly because the techs have not gone through the training, the sensitivity training, and they don't have the nurse's training, either. People think it's just good enough to know how to fix the machines, and you know, set up the machines, and stick you. But you know, it's a lot more to it than that, and I don't think they're given the training.

Theme Four: Fatigue

- And then one day, it was Thanksgiving in 1995, I just wanted to lay in my big chair and to hell with it. I was just tired and logy and just didn't feel like doing anything.
- My energy, it goes up and down. Based on how good a run I have. Lately I've been so damned tired I haven't done anything. I just sleep.
- Now the problem I have on it, you get home and probably three or four hours, my body's pretty tired. It's funny how just sitting there leaves you so tired out, cause even if I sleep there, I still go home and feel tired. The longer you're on it seems like the more that happens. The first couple of years I was on, I didn't really notice it. But now that I've been on hemo this long, it does bother me more than it did. The tiredness. I get pretty exhausted when I get home. Sometimes I sleep, sometimes I just sit in the chair and watch TV. I have to get off my legs, cause my legs get real tired.

Mostly it's just my legs. But if your legs are tired, you're tired all over.

- But if I gain a lot of fluid, sometimes I feel lousy after dialysis. When I come home, I'm just whipped. And my mom can always tell. I go to bed early. Or I lay in my bed and watch TV. But like I said, if I got more than three kilos on, I'll come home just whipped. A couple of times my mom had to come get me because of it.
- Tired! You know, you're tired all the time. You know, when you come home, when you first start coming home, they say, "How do you feel?" and I'd say, "Okay." I didn't know you were supposed to feel any better. Oh, I used to have a love seat sitting over there, and my husband would take off my boots, take off my coat, and say "Dear, why don't you go lay down?" I'd say "Okay", and lay there for two or three hours and sleep. Just could not move. Just tired, just drained.
- But there was so much I couldn't do, like I'd say, "I think I'll get up and do so-and-so, or such-and-such", and I'd get to the kitchen and all I could do was sit. I used to sit to wash dishes, sit and peel potatoes, sit for everything.
- But I was so tired, I'd get paid on Wednesdays and I'd be too tired to even go cash the checks. It was pitiful, pitiful.

Theme Five: Dietary Restrictions

- If you want quality of life, you'd better do it and do it right! As well as your diet. You know, the importance of the diet. And you

better stick with it. You can't go out boozing and all that jazz.

Cause it's tough, I mean you can, but it's going to be hard on you.

You'll have a lot of cramps. That's what happens.

- I behave myself as far as fluid intake. And people don't understand that very well, either. They're told about it, but they don't really understand the importance of it. Back off, and don't abuse your body. What I've found, too, is sucking ice cubes when you're thirsty. What I do, is I take a glass of water, I rinse my mouth out with it, with the water. I'll do that twice with cool water, and then drink a little bit, don't fill the glass up, maybe fill it half full.
- Um, as far as, um, my personal life, it's changed a lot for the simple reason I can't drink a lot of fluids. That bothers me. I can eat about anything, but you got to watch your intake on your potassium and phosphates.
- If I go someplace, I know just about how much fluid intake, and if there's any fluid in the foods I eat, so I have a pretty good, I know, without following the diet straight, what I can take in.
I don't get dizzy, but I do get cramps. I get quite a bit towards the end of the run. But that's a lot of the time cause I put a little bit too much fluid on.
- So now I try to eat, even if I'm not hungry. Half the time I'm not hungry. And I don't eat a lot at one sitting. So sometimes I have peaches, or fresh strawberries, or blueberries, them are next. Then I was eating steak for protein, but they told me it was high in phosphorus, and my phosphorus is high. Like I said, you can't win for losing. They want you to eat 70 of protein, 70 grams of

protein a day. There's no way! No way. Especially when you've gotta watch your salt.

But what hurts me more is my jello. I can't have my jello. Or water. Or potatoes. Green beans. Bananas. That's what I miss.

- I do fear, sometimes, that I've had a little too much potassium. But I've done that only one time in over nine years, had too much potassium. Now I know what to do, is, if I have spaghetti today, and it's on a Wednesday, well, Thursday I'm sure not gonna be eating banana pudding! So that's the way I do it. Or if I happen to eat French fries that haven't been soaked, then definitely, I'm not eating anything that's high in potassium until my next dialysis.

Theme Six: Travel and Mobility Restrictions

- I didn't want to be tied to a machine, and my job involved so much traveling, you know, that's kind of tough.
And then this travel thing is, it's really important. Because you've got to realize you can travel, and people are scared of the unknown. But, the hardest thing, like I say, about getting on a kidney machine is, in the U.P., they got three units, but usually I can only get in one, cause the other ones are all filled up. And it's a big problem with kidney failure, every place you go.
- No, you can't pick up and go. It makes it rough.
- But usually I don't like going too far from the house. I feel safe here, I guess.
- And, um, it was just so terrible, because I always liked to travel, I couldn't travel. I didn't have the money.

- I miss traveling, and I miss shopping, cause I was in Tupperware, and in Tupperware, there was three times a year we went shopping. We went on a trip. And being Jehovah's Witnesses, three times a year we went on a convention. I don't do that now, so I miss all that, um, all that.

Focal Meaning Three

Acceptance and Outlook on the Future

Theme One: Striving for Normalcy

- But I worked out a deal. I actually bought the catalogue for traveling from the government. Whenever I had an assignment and I had to travel, I'd go ahead and line up all the necessary paperwork and everything else. I could see that our clinic wasn't used to having people travel a lot. And so I did it myself.
- For the simple fact that I can go back to leading a normal life. Go places I want to go, do what I want to do. More freedom, that's what it would be. More freedom.
- And if you're doing everything you want to, then all of a sudden you can't. I mean, that's a big shock. Liable to be a big shock to the family, but more shock you.
- Sometimes, I wonder what it would be like if my kidneys just miraculously started working again. I don't know. I'd have more fun, I guess. Probably get a job. Have a normal life.
- Sometimes I sit and think, instead of getting lupus, I could of kept my job I had in '82, could have found somebody and got married, had kids.

- So hemo has stopped me from doing some things, but the important things it hasn't.
- You know, I hear the patients say "We can't have this, we can't have that", and I eat canned tomato soup and grilled cheese sandwiches! I love it. But I'll eat it on a Wednesday, maybe when I come home from dialysis. and you better believe I don't eat the whole can! And Thursday, I'm real careful.

Theme Two: Attitude

- But the main thing is you've got to adapt to your situation, it's going to be there, it's part of life, and you just roll it right into your life. That's what it is. And accept it from a positive point of view. Then it's a matter of adapting your attitude. This is life, this is real. And you'd better accept it as such and integrate in into your lifestyle, because it's not going to change.
- I guess to sum it all up, it's mostly your own attitude. How you feel about making it through life and still maintaining high quality. Cause I have highs and lows just like everybody does. You can have quality of life. If you organize your business properly. I see a lot of people go completely disabled or take advantage of the system, getting income from the system, and so on. But I'm not like that, I couldn't do that.
- I've never missed a treatment. Never been tempted to skip. Never even thought about skipping. I figured that's what would do me good.
- I don't think about it too much. Cause like I said, I get upset some-

times. If I feel myself brooding, I quick turn on the TV, or go take my dog for a walk in the backyard.

- I'm actually happy. I don't have any reason to be sad.
- Dialysis don't bother me. I don't think about things I can't control. Now I've learned to live with this. It's been almost ten years, and it just makes me feel, well, who's two say it couldn't be another ten? But if it isn't, ten years has been a long time on dialysis. I've seen so many people come and go there. That I've been really fond of.

Theme Three: Transplants

- And my attitude on transplants, I really don't believe in them, because, you know, they fail. Some guys have two or three separate kidneys, and then they go back on hemo. I say, hey, I know what it's like to fight this thing. And so on hemo I feel better and have better quality of life than these kidneys failing. Cause you know, you have to take this rejection drug, too. Which is bad news. I don't like prednisone, I hate it. I hate prednisone.
- I'm on the transplant list over to, um, over to Mayo. I think, or whatever it's called over in Minnesota. They put me on the list there, I went over there, I think in '95, they said it would probably be three to five years. I called just recently and they said they don't have any idea, but they said that I should be getting close. But I got O positive blood, and that's the type of blood that needs a lot of kidney transplants. If I had a different type of a blood type, I'd probably already have one. I'm hard to match cause I'm O

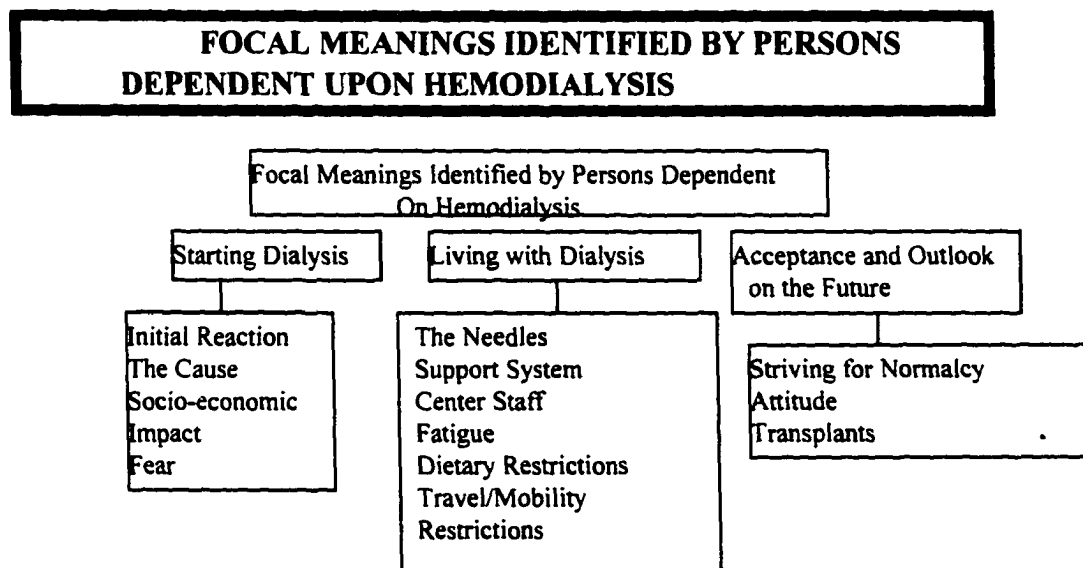
positive, and there's so many on the list. So they don't have any idea of how close I am to getting one. They told me it would be maybe up to five years, well, it's gonna be four years in August. It's a long wait.

- Then you gotta be on three kinds of anti-rejection medicine. Medication that makes your face swell up. You've probably seen people that have come back and had their faces all swole up, that's what causes it.
- I always carry my beeper with me, I just slip it in my purse so I don't forget it. I never forget it. I can't walk out the door without it. It's for my transplant. Nobody else has the number, just St. Mary's.
- It's scary. Cause the first time I had a bad time. And I'll be in Grand Rapids. All my family is here. My mom can't run down there every day.
- So I can go out and be normal. Go to Parties in the Park, go to the lake. Now I won't wear a bathing suit in public. I won't. I don't hang around with my friends.
- At the first two years, I didn't think I wanted a transplant. I had had so many surgeries in my life that I never wanted to have surgery again. And then I don't know if you remember Mr. (former patient). He got a transplant from one of his family, and then I thought, oh, that would be nice! He was gonna drive down south, going visiting, and he came back looking so good, so fat. Then they were supposed to send me to St. Mary's and they rejected me. And also, Beaumont did. Because of being a high risk, having had a heart attack, my circulation, which if they did it

they said that they'd have to do some kind of 'gram first. And of course not taking blood. They can do the surgery without blood, at Beaumont, because it's considered a high risk hospital. But they wouldn't for me because of the other things I had wrong with me, too.

- No. No. It wasn't a big letdown for me because it was never a priority.
- But definitely I would not ask anybody to give me a kidney. No way. I just wouldn't, it would just be something I just wouldn't ask anybody to do.
- And then I didn't think I wanted someone else's organ in my body! But the transplant was never a priority.

The following model was devised based on the co-participants' descriptions and included the three focal meanings of starting dialysis, living with dialysis, and acceptance and outlook on the future.



CHAPTER V

Discussion

Findings

The perceptions and descriptions derived from the interviews of four persons dependent upon hemodialysis for survival demonstrate the need for and the value in this study. From these perceptions, three focal meanings emerged; a) Starting Dialysis; b) Living With Dialysis; and c) Acceptance and Outlook on the Future. Each focal meaning signified a step in coming to terms with and learning to live with each individuals' perceptions of their lived experiences. The co-participants each provided descriptive elements related to the focal meanings.

Starting Dialysis: Each individual recalled with extreme clarity how and when they were informed by their health care provider that they needed to begin dialysis. The co-participants for whom the need for dialysis was a surprise recalled an emotionally turbulent time, with feelings of anger, depression, fear, and grief. Those individuals who had been aware of their disease processes and that dialysis was a future probability related that they had much less mental anguish over the announcement, verbalizing more concern for the anticipated disruption in their day-to-day lives.

The cause of their renal failure was also significant for each co-participant, whether it was a disease process they could do nothing about, one they could but chose not to, or a medication-related adverse reaction. The co-participants who had suffered from long-term illnesses and did not follow the prescribed treatment program relayed feelings of guilt, self-blame, and depression.

Each individual related descriptions of how being dependent on hemodialysis affected their ability to continue working. Of the four co-participants interviewed, only one was able to maintain employment, and at considerable effort and inconvenience to himself. The others felt too limited by either their physical or mental condition, and/or

time constraints to pursue employment. All co-participants described a decline in income and an increase in expenditures.

Each co-participant was very clear in the understanding that hemodialysis was keeping them alive. Each person was adamant that a treatment would never be missed, and the plan of care should be followed. All verbalized acute knowledge of the threat of death from too much deviation. Some directly admitted to fear of not living to see next year, and some flatly stated that they didn't think about that sort of thing.

Living With Dialysis: The large bulk of the interviews' content centered on issues pertaining to the here and now--what the co-participants experience now while living on dialysis. If frequency of mention is any indication, the needles used in hemodialysis to access the vasculature are of utmost significance. Each related continued fear and pain due to the large size of the needles and the frequency with which they must be used. Each co-participant had stories to share about the bad experiences they've had with needle placement.

Being dependent on hemodialysis was eased for each individual by the support systems they had in place. The majority of the co-participants left no doubt that their spouse and/or family was the biggest help in terms of support. One co-participant made little reference to family at all, and indicated that she had received tremendous support from her faith and her church. Another described the rejection and self-esteem problems suffered when her friends slowly drifted away.

The staff at the dialysis center also became an influence to the co-participants. They viewed the staff members as friends, partners in their treatment, and valued establishing and maintaining good relationships with them. Some concern was verbalized by the co-participants regarding the hurried pace of the center operation, and feeling rushed, objectified, and even sometimes fearful regarding the competency of care being provided.

Each co-participant, in describing the experiences of living with dialysis, included the difficulties of battling frequent fatigue following treatment, coping with the rigid dietary restrictions, and the limitations of ability to travel. Each had choices to make regarding these issues, such as whether the tomato soup is worth the risk, or whether the weekend vacation is worth the hassle of making the arrangements.

Acceptance and Outlook on the Future: Striving for normalcy was a theme that was intertwined throughout the interviews with the co-participants. Each individual had learned his or her own limitations in terms of “cheating” on the strict dietary restrictions, and felt this gave them a measure of personal control. The individual who continued working and made his own travel arrangements found a great deal of personal empowerment from doing so. Some individuals looked forward to kidney transplants for the purpose of increasing the normalcy of their lives. Each perceived hemodialysis dependency as a barrier to normalcy.

Developing a philosophy of acceptance and a positive attitude was verbalized by the co-participants as important to survival and maintaining quality of life. They were quick to recognize brooding or depressive behaviors in themselves, and were pro-active in changing their own outlooks. Each recognized that attitudes of acceptance and taking responsibility for their own behaviors rewarded them with better health.

The issue of a kidney transplant was raised by each co-participant, with the majority looking forward to transplantation in hopes of increasing the normalcy of their lives. One of the individuals was not interested in transplant, as he perceived it as a temporary fix with a great deal of side effects.

Literature Review

In phenomenological research, the literature review is conducted after the data are collected and analyzed. The purpose is to compare the findings from the literature to the findings from this study.

There is a large volume of research available pertaining to the hemodialysis-dependent population; However, the vast majority is quantitative and related to specific issues of treatment. Only one qualitative study that addresses living with renal failure was found in the past ten years of literature review. Quantitative data that are pertinent to the issues raised in this study is also included.

Starting Dialysis:

The process of starting hemodialysis and coming to accept it as part of life was a theme also identified in the phenomenological research dealing with living with renal failure (Rittman, et. al., 1993). The findings of that study revealed how patients moved from an initial coping period to “taking on a new understanding of Being”.

In an informal, unstructured interview (Rosenblum, 1995), hemodialysis-dependent novelist James A. Michener identified his own initial reaction to kidney failure:

“I was amazed when my kidneys started to fail, and I was very scared. My ankles were the size of cantaloupes. Being the kind of person I am, this was really another challenge in a series. I didn’t know what was happening, but the doctors explained it to me and knew just what to do. I’m tremendously delighted and relieved that scientists in the period before I became ill had perfected a way of treating renal failure. I am far from depressed, just the opposite! I lucked into a disease that is manageable. It is a heavy assignment, going to treatment three times a week, three hours a day, but I’ve learned to live with it.”

Other quantitative studies identify depression, denial, dependency, and helplessness as typical initial reactions to dependence on hemodialysis (Cohen and

Tucker, 1994; Sacks, et.al., 1990; Rydholm and Pauling, 1991; Rodin, 1994; Bremer, et. al., 1995; Devins, 1994).

The socio-economic impact of becoming hemodialysis dependent is acknowledged by the subjects in a study by Gurklis and Menke (1995); Many reported restricted lifestyles from inability to work due to their illness, or they perceived insufficient retirement/disability benefits to cover their health and living expenses. A more intense work researching the factors contributing to the ability of hemodialysis-dependent persons to maintain employment was published by Curtin, et.al., (1996). According to Lore (1994), an ongoing study is underway to further identify ways to better meet the needs of dialysis-dependent persons undergoing vocational rehabilitation. Witten (1995) also identifies barriers to employment for dialysis patients.

Living With Dialysis:

Pain and fear associated with needle placement was addressed by the co-participants in this research as a major concern. It is therefore surprising that no research was found in the literature review pertaining to this issue.

There are numerous articles of research that support the importance of social support in adapting to the accepting hemodialysis dependency (Gurklis and Menke, 1995; Flaherty and O'Brien, 1992; O'Brien, 1990; Reiss, 1990; Devins, 1994). Likewise, there is research to also support the idea that dialysis center staff can either increase or decrease the objectification, or loss of personhood, that is a potential perception of the hemodialysis-dependent person, and to maintain the "human connectedness".

In the qualitative study by Rittman, et.al., (1993), food and fluid restrictions were identified as a major problems in living with dialysis. Another common response to dialysis was severe weakness, with co-participants describing a "washed-out" feeling following dialysis and often spent the remainder of the day in bed.

The quantitative studies available also support the idea that the dietary and fluid restrictions are a major concern for hemodialysis patients (Gurklis and Menke, 1995; Lev

and Owen, 1998; O'Brien, 1990; Hakim and Levin, 1993; Simmons and Abress, 1990; Bergstrom, 1995; Bremer, et.al., 1995). The restrictions are identified by the co-participants as a stressor, and coping mechanisms are identified.

There has been no research published within the past ten years related to the post-treatment fatigue reported by the co-participants of this study. The fatigue is commented upon in the qualitative study by Rittman, et.al., but there has been no research published as to its basis, or to substantiate any proposed interventions.

The difficulty of traveling was addressed as a concern by the co-participants of this study. In reviewing the literature, there was little mention of the travel and mobility restrictions imposed on this population. The wife of hemodialysis-dependent man writes (Harper, 1997):

“Fortunately, George began to feel better, and with the choice of home dialysis was able to continue his job (the dialysis clinic in our town did not offer a shift after work hours). We were eager to resume traveling, which we both enjoyed. However, we soon found that when we wanted to travel, it wasn't always when a space was available for dialysis at a clinic, and George found he became increasingly less comfortable giving up control of his treatment to the unknown staff”.

Acceptance and Outlook on the Future:

The co-participants in this study describe mechanisms by which they strive for normalcy in their lives. Some push the limits of their dietary restrictions to maintain a sense of control, some look forward to receiving a transplant, some make extraordinary efforts to travel and maintain independence. In the study by Rittman, et.al., (1993), the participants related that the initial disruption in managing daily life was gradually replaced by what came to be as a “normal day” and a “normal way of being.” In a descriptive survey (Gerbils and Menke, 1995), dialysis patients also identified leading as

normal a life as possible as one of their greatest priorities, and described coping mechanisms to assist toward that end. Numerous studies explore compliance behavioral mechanisms to assist toward that end, attempts to maintain normalcy (O'Brien, 1990; Meers, et.al., 1995; Valdez 1998).

In looking to the future, each dialysis patient considered the idea of renal transplant and how it would impact his or her situation. Some viewed transplant as the key to returning to the "normal life" left behind at the onset hemodialysis dependency. Others saw another surgery, a procedure with side effects and continuation of a strict medical regime, albeit different from the current regime, and not worth the investment. McDonald and Aultman (1993) discuss a group of renal transplant recipients whose allografts are in objective and subjective parameters in evaluating quality of life as compared with hemodialysis. Helderman (1998) claims that the success of transplantation allows a great number of patients to lead normal, healthy lives, but that this does not automatically erase the stresses of employment and interpersonal relationships and the need to live a balanced, healthy life.

Each co-participant in this study identified their perception that developing a positive, accepting attitude was significant in terms of maintaining health and a sense of well-being, including ownership in their health care and providing a sense of maintaining control. In the Rittman study (1993), this concept is identified as maintaining hope. Maintaining hope was described as a relational theme that described the importance of seeing new possibilities in coping with a chronic illness. In their descriptive survey, Gurklis and Menke (1995) found that thirty percent of their participants identified striving for a positive attitude as one of their most used and most effective coping mechanism. Subjects kept a positive attitude by having realistic hopes, keeping life as normal as possible, and perceived themselves as being healthier than before starting dialysis treatments.

Conclusions

The co-participants in this study, “The Lived Experiences of Persons Dependent on Hemodialysis”, identified meanings and themes that are only partially consistent with the concepts being studied in current literature; An example of this is the theme of “the needles” identified by the co-participants in this study, which had no current research available.

Co-participants identified three focal meanings: 1) Starting Dialysis, 2) living With Dialysis, and 3) Acceptance and Outlook on the Future. Each focal meaning contained themes that were common between co-participants. Starting dialysis provoked different reactions in the co-participants, with the cause of their renal failure and the time they had to process the information as leading factors in their reactions. Fear and financial concerns topped the list of initial concerns when starting hemodialysis. As hemodialysis became “routine”, new issues developed as they entered the “Living With Dialysis” phase; These included the fear and pain associated with the needles, the influence of their support system and the dialysis staff, travel and mobility restrictions, adjusting to dietary restrictions, and learning to cope with the fatigue following treatments. The co-participants identified the importance of developing an attitude of “Acceptance and Outlook on the Future”. They had all incorporated activities or perceptions into their lives to facilitate “striving for normalcy”, and consciously worked to maintain positive attitudes. The option of having a transplant was based on their perception of its potential impact on their independence and ability to maintain normalcy.

The emphasis of current research is however, not consistent with the emphasis of identified concerns and themes identified in this study. The vast majority of available research on the hemodialysis-dependent population is quantitative, with distinctly medical, and medical problem-oriented focuses. The themes identified by the co-participants in this study were related to the impact of dialysis on their daily lives,

where as the current body of research looks at the impact of patients' daily lives on the efficacy of their treatment.

Implications and Recommendations

The focus of phenomenology is to describe the experience as it is lived (Oiler, 1982). It is the major task of phenomenology to elucidate the essences of the phenomenon under investigation, including not only the phenomenon in itself but also the context of the situation in which it manifests itself. Phenomenology is particularly appropriate for the sciences in which Man's humanness and connection with the world are the point of inquiry (Parse, et.al., 1985). This concept is particularly applicable to the hemodialysis-dependent population.

Researchers have been drawn to the unique population of hemodialysis-dependent persons since the beginning of treatment availability. Research has been done by a large variety of disciplines, including physicians, nurses, dietitians, social workers, and psychologists. Each discipline, as one would expect, focuses their research priorities within the context of their discipline. Unfortunately, phenomenological research using qualitative methodologies is lacking. Qualitative research methods are essential to gain a holistic perspective of phenomena. Human beings need to be understood from the totality of their lifeways, bearing in mind the dynamic interplay of these lifeways with social, economic, political, religious, and cultural values within historical and meaningful life events. Discovering holistic patterns and themes of phenomena is the way to understand people and their caring lifeways and needs (Leininger, 1985).

The experiences of individuals, beginning at the time of diagnosis, are unique and individual, while many of the responses to the experience are similar. The responses and priorities of the individuals participating in this study are incongruent with the current body of research. The themes that emerged as having the greatest impact on the participants were noticeably absent or lacking in current research.

Recommendations

Being dependent upon hemodialysis for survival has far-reaching implications. The dialysis-dependent person has many issues to contend with, not only the physiological changes, restrictions, limitations, and new responsibilities, but also the changes in all aspects of their daily life. They cannot eat or drink what they choose, they have limitations on where they can go and for how long, financial constraints, social changes, and live with the knowledge of their severely reduced life expectancy. They have to face the pain and anxiety of needle placement, deal with post-dialysis fatigue, and endure an environment where they often feel objectified and de-humanized.

This study has increased the knowledge and understanding of the need for increased awareness of the special needs of this population. Additional qualitative studies are needed to better define for research priorities, and interventions are needed to better address the identified priorities of this population.

Summary

This study has identified and described the lived experiences of four people who are dependent on hemodialysis. It represents a continuation of the process of discovery and awareness of the phenomenon of hemodialysis dependent persons. Findings of this study are partially consistent with previous studies, and provide additional perspectives for consideration by healthcare personnel and researchers.

This study has identified common meanings and themes associated with the lived experiences of being dependent on hemodialysis, and identifies the need for increased awareness among healthcare personnel of the issues that are of great importance to this population. It also identifies a need for additional qualitative research to better define research priorities and develop interventions to address the themes identified by hemodialysis-dependent people.

APPENDICIES

Appendix A
Poster Requesting Study Participants

Request for Study Participants

Volunteers are being sought to participate in a study that is being conducted to examine the lived experience of persons dependent upon hemodialysis. The study is being conducted by a registered nurse through Grand Valley State University.

Participants will be asked to describe the experience of being dependent upon hemodialysis in a tape-recorded interview. All information is kept confidential.

If you are interested in participating, please fill out a respondent card and submit to the Clinical Manager.

Appendix B
Respondent Card

Respondent Card

I am interested in participating in the study exploring the lived experiences of persons dependent on hemodialysis.

Name: _____

Date: _____

I hereby give permission for the registered nurse who is conducting the study to contact me at home.

Phone: _____

Best time to call: _____

Appendix C

GRAND VALLEY STATE UNIVERSITY

HUMAN RESEARCH REVIEW COMMITTEE

Principal

Investigator: Molly A. Kidner

Department or School: Grand Valley State University

Address and

Telephone: 2895 White Lake Drive, Twin Lake, MI 49457 (231) 828-4440

Title of the Project: The Lived Experiences of Persons Dependent on Hemodialysis

Summary of the Project: The purpose of this study is to seek a fuller understanding of and to identify the underlying themes of the lived experiences of persons dependent on hemodialysis through self reflection on thoughts, feelings, and perceptions related to this experience. The Husserelian phenomenological method of research will be used to examine this phenomenon. Participants will be enlisted through a local outpatient hemodialysis clinic and data will be collected through face-to-face tape-recorded interviews.

In what capacity does this project involve human subjects: (E.g., surveys, interviews, clinical trial, use of medical records, etc.)

Patients will be selected from a local outpatient hemodialysis clinic, and will reflect upon their lived experiences through a face-to-face tape-recorded interview with the researcher.

Check one:

☐ This is a report on research on human subjects which is exempted by 46.101 of the Federal Register 4616.8336, January 26, 1981. (Refer to instructions on the reverse of this form.)

☒ This is a request for expedited review as described in 46.110 of the Federal Register 46(16):8336, January 26, 1981. (Refer to instructions on the reverse of this form.)

☐ This is a request for full review. (Refer to instructions on the reverse of this form.)

Principal Investigator

Department/Unit Chair and Advisor

Date

Date

Note: proposals which do not include a summary of the project and which fail to respond to the requirements stated in the instructions for applicants (on the back of this form) will not be considered and will be sent back to the authors.

5/97

Appendix D
Grand Valley State University Human Subject
Informed Consent Agreement

PURPOSE:

You are being asked to participate in a study conducted by Molly A. Kidner, RN from Grand Valley State University, Muskegon, Michigan. The purpose of this study is to examine the lived experiences of persons dependent upon hemodialysis. You have been selected as a possible participant for this study because you have identified yourself as a person dependent upon hemodialysis.

PROCEDURES AND DURATION:

If you agree to participate in this study, you will be interviewed by Mrs. Kidner at a mutually agreeable location. You will be asked to describe your experiences as a person dependent upon hemodialysis. The interview will be tape recorded so that your description can be obtained with accuracy. This recording will then be transcribed into written text, and the tape will be destroyed by the researcher immediately following transcription. This interview will require approximately one hour of your time. You will then be contacted within two days of the initial interview. At that time you will have the opportunity to clarify anything from the interview.

RISKS AND DISCOMFORTS:

A possible detrimental effect associated with participation in this study is that describing your experiences may cause you some anxiety. The social workers at your hemodialysis unit have agreed to be available for referral regarding any such effects. There is no cost to you for participating.

BENEFITS:

The results of this study will provide information that will enable nurses and other care providers to identify the unique needs and to better assist person dependent upon hemodialysis and their families meet those needs.

CONFIDENTIALITY:

Your identity will not be revealed while this study is being conducted or if the study is published. All results will be described without using your name.

VOLUNTARY PARTICIPATION:

Participation in this study is voluntary. You may decide not to participate or stop your participation at any time. This will not affect your relationship or future relationships with health care providers or Grand Valley State University.

OFFER TO ANSWER QUESTIONS:

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

AUTHORIZATION:

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THIS STUDY. YOUR SIGNATURE INDICATES THAT YOU HAVE READ ALL OF THE INFORMATION PROVIDED ABOVE, HAVE HAD ALL YOUR QUESTIONS ANSWERED, AND HAVE DECIDED TO PARTICIPATE.

Date

Name of Participant (please print)

Signature of Participant or Legally
Authorized Representative

Relationship to Participant

Witness

If you have any questions concerning this study or consent form beyond those answered by the researcher, including your questions about the study and your rights as a study participant, please feel free to contact the researcher, Molly Kidner, at (231)828-4440 or Professor Huizenga, Chair, Institutional Review Board, Grand Valley State University at (616) 895-2472.

Appendix E
Telephone Script

My name is Molly Kidner.

I am a registered nurse and a graduate student at Grand Valley State University. I received a message from you that it was okay to contact you about participating in a research study I am conducting.

The purpose of this study is to look at the lived experiences of persons dependent on hemodialysis. I hope this study will enable nurses to better understand the needs of these people and assist in meeting those needs.

What we will do:

1. Interview you at a mutually agreeable location.
2. Ask you to sign an informed consent, which is a document stating the risks and benefits of this research as well as assuring your identity will remain confidential.
3. Ask you to describe your experience as a person dependent upon hemodialysis.
4. I will tape-record the interview so I can be accurate about what you have said.
5. Your identity will be protected and not revealed in any way.
6. If you wish to have someone present during the interview, please limit it to one person. That individual should not prompt you or contribute to the interview in any way. Their presence is solely for your support.
7. I will call you within two days of the interview. At that time, you may clarify any statements made during the interview.

This is voluntary. Do you have any questions?

Would you be willing to participate?

When is a good time for you?

Directions.

Appendix F Interview Transcripts

Co-participant # 0102025

I'll start by telling you how I felt when I first got on dialysis. When I first started dialysis I didn't know my kidneys had failed and I didn't have insurance. And so I wasn't particularly going to the doctor and taking care of myself like I should have. A year before, in 1989 in January, I had started a new job where they gave you a complete physical and I wanted the job for that reason, and they told me I had protein in my urine. And so I had to take a 24 hour urine, collect my urine for 24 hours. And I got the job, they told me to follow up with my doctor, which I did, and then I worked a whole year not realizing how bad my kidneys were. Well, this was in January of '89, and in Jan of 90, a few weeks or months before that, I was tired all the time and could barely walk, barely walk. And so I went to the outpatient clinic, where my doctor was, and he wasn't there because he had just had surgery on his back. Another doctor came back in just a few minutes and told me the bad news, your kidneys have failed. So he sent me to the hospital, I went to the hospital, I had a test, and I went home. As soon as I walked in the door, they called and said can you make it back out here? I says yes. Are you sure you can make it, they says, are you sure you can make it OK, and I says yes, sure I can. So I went back out there and they told me my kidneys have failed, you have to go on dialysis, and they sent me over to Mercy to see Dr. Downer. So that's what I did, I was very, very, very devastated, very devastated because I didn't have any medical insurance and, um, it was just like, I would always use the phrase that I'd been "laid off from life". You know, because I've always had a job, since I was 16 years old, and, um, it was just me and my sister, we didn't have to work, it was always just what I wanted to do was work. And I always took care of my kids, you know, I didn't think you should work if you couldn't take care of your family. So I was always doing something, and then I didn't have anything to do, I couldn't do anything and I had to take care of just me. I went on PD first, and I felt so guilty for taking care of just me, and not being able to do anything. At all. So I was able to come home after 3 weeks with PD, and I had trouble with PD because I had had a lot of abdominal surgeries and I had a lot of scar tissue. And with that, I didn't drain, it would take me an hour and a half to drain. And each day I'd get bigger and bigger and bigger because I couldn't drain. And so I was always tired. I wouldn't allow anybody to do anything for me except put my PD bag in the microwave. I was so afraid of the infection they told me I'd get. I was, actually, I guess I was depressed but I didn't realize it. At no point did I ever, ever say "why me". I had so much guilt at knowing I should have taken better care of myself, and I realized that it was more or less my own fault. The nurses would tell me, though, "you don't know, it's not your fault, you never can tell", and I says, well maybe I wouldn't have gotten it as soon. But I feel, you know, if I had taken better care of myself... So I was really depressed about it, you know, and I had, and then doctor told me I should go on hemo for one week, just to see how things went. Well, that first day on hemo, I was so thrilled because I was on for 4 hours, they took off 12 kilos

12 kilos?

Right. And at that time they always had an RN with you for your whole 4 hour run. I mean, and so I was able to talk to her and I learned a lot. I learned a lot on PD because you get really good training on PD. They really trained you, you took tests and everything. So when I came on hemo I knew a lot of what was going on. I mean, she talked to me for 4 hours. And when I got home I thought, geez, you don't have anything to do until Wednesday. 'Cause I cried before. And I thought, well I guess I can do this. So after a week, he says "I guess you better stay on hemo". And that was OK, cause when they put my line in for PD, they also put my line, or graft, whatever, in my arm. They put that in on a Monday. They probably realized then that I wouldn't be able to, you know, do PD, cause they kinda tried to talk me out of it. After that, I would feel really depressed. But, well because I couldn't do a lot, and that kinda bothers me. And my husband and I have 2 different personalities. He would do everything for me, and he's a clutterer (hahaha).

Why is it you couldn't do a lot?

Tired! You know, you're tired all the time. You know, when you come home, when you first start coming home, they say "how do you feel", I'd say "OK", I didn't know you were supposed to feel any better. And they would take too much off and oh, I used to have a love seat sitting over there, and I'd come lay in the love seat and my husband would take off my boots, take off my coat, and say dear why don't you go lay down, I'd say OK, and lay there for 2-3 hours and sleep. Just could not move. Just tired, just drained. That's the way I think a lot of them are, and I try to tell them it'll get better, just be patient, be patient, like Colleen, when she first started to run, I'd talk to her and tell her "you'll feel better" cause after a while you really do start to feel better. But there was so much that I couldn't do, like I say "I think I'll get up and do so-and-so or such-and-such", and I'd get to the kitchen and all I could do was sit. I used to sit to wash dishes. I don't do that anymore, but I used to sit and wash dishes, sit and peel potatoes, sit for everything. And, um, it was just so terrible, because I always liked to travel, I couldn't travel, I didn't have the money. My husband was on workman's comp, he had been on for several years, and I wasn't bringing in any money, so there was so much I couldn't do, and I would get so depressed about the medical bills, and Dr. Twu was so good to me when I came home from the hospital he went to his office, it was on a Saturday, and he went back to his office and he got me all of those sample medications that I needed because I didn't have any. I guess I love him today, because I was so worried about it and he was able to do that for me. And, but now, I don't do a lot, and I enjoy being home, I enjoy being alone. Hard to believe but I love it, I just love it. But I used to lay down a lot. And then I thought, my grandchildren would come over and yell where's grammy, where's grammy, and they'd run right to the bedroom. Then one day they said where's grammy, when I wasn't there, and I thought, they're going to grow up and remember "when I was young, my grammy stayed in the bed all the time" (hahaha). So now, I never stay in bed, never stay in bed. I have a recliner chair, and I do stay up there. And I do find that, like I told one of the patients a few weeks ago, she was complaining all the time, complain, complain, complain. And, I told her, I thought, I'm gonna tell her someday, I just can't continue with this. She'd complain because, the new people they have, it's so different, things have gone downhill, the nurses don't do this or that, they always say can you wait until I get my blood pressures done, you know, and stuff like that. And she said that, and you know, I said "you know, I'm one of Jehovah's Witnesses, and I think Jehovah has given me a blessing, giving me hemo. And he gives nothing but good gifts. And by getting his gift, I would never, ever question that gift that he gave me." And I said "and how would I live if I didn't have dialysis?" And she said "yeah, but you know, they always say to wait a minute or hold on a second or won't let me go home if I wanna go home" and I says, "yeah, but what do you do? If I wanna go home, I go home. I just tell em if I am so sick cause I never ask to go home unless I am just too sick. And I just can't stay here. And so they let me go. And now she doesn't complain to me. (hahaha). You know how I feel, I feel very, very thankful that I have my religion, because my religion is what helped me. Because the friends of the Kingdom Hall where we go, they was always just so good to me. Just, just good, and that helped me. My family has always been there, and that helped. And my mother, especially, because the first few years my mother was in perfect health, and I used to say, um, I'm so blessed, because what if she was sick and she needed me and I wasn't able to help her? Because she'd bring me meals, she'd say "just tell me what you want, I'll fix you a nice meal", and all that kind of stuff she did for me. It was so wonderful, and when she got sick, which was about 3 years ago, I was able to have her come and live with me. The doctors would say "well, you can't do that", and "don't you do anything with that arm", you know, and "make sure you get hospice to come in". And when she came to live with me my sisters pitched in, my daughters, my niece, everybody, all my relatives. You know, this is unbelievable because my family, I wasn't too close to them. My uncle would call and say what do you want for supper, and I'd say Uncle Benny, you don't have to do that, and he'd say no, they want to do it. They'd make our whole supper. And even her sister-in-law's sister, who wasn't any relation to us, she would bring meals. And one of my kids or sister would come over every day, say "I'm takin these home with me to wash", my sister would get off work at eleven o'clock, she'd be here 5 in the morning so I could go to dialysis, and she would stay until another lady would come at 11. And when my niece would get off work at 12 she'd come over there and stay. From 10 o'clock until 12 she would stay. So you know there was just always somebody here to help me. And that was a blessing. So hemo has stopped me from doing some things, but the important things it hasn't. In fact, hemo has brought my family closer together. I can't say it was dialysis itself, its just that I've been unable to do lots of things I thought I was the only one in the

world that could do. (hahaha). Just do it all.

Sounds like you learned a lot about yourself and your family.

Oh I did, I did. In fact, I had another nurse, I don't know if I told you this or not, working on her paper interviewing me, and she wanted to get done by Thanksgiving. I think we had 8 or 9 weeks until Thanksgiving. And she had to write a paper too, and she wanted to know how she could help me set a goal. She wanted to know how I feel about, you know, from 1-10, how did I feel about how my life is. And I gave her probably a 10 or 11, because I do, ultimately, feel so strongly about my religion, and it's helped me so much and I realize the promises that it gives me. But I wasn't going to my meetings, you know, because I had this telephone, a hookup right there, and all I do is call up and I listen to the meetings, they've provided that for me. And I did it faithfully, on Sunday we had 2 hours, one hour on Monday nights, and Thursday night 2 hours. So that's what I would do but I would feel guilty because there were a lot of things where I felt good enough to go. But it was handy, so you know, why you know. You had to put on dressy clothes, too. (hahaha) And so I felt guilty, and when she says, what was my goal, I says well, my goal was to go back to the meetings. She says we should set small goals at a time, maybe just one meeting. I says no, my goal is to go to all the meetings. She says OK, and I gave her a goal, I would go the Sunday after Thanksgiving is when I would go. Well, she didn't come after that, and that Sunday, I had to go, I had promised her, couldn't lie to her. You know, so I had to go! So I went and when I got there, one of the elders said, "Oh it's so good to see you" and I said I just want to let you know, I'm not listening to the telephone anymore, I'll be there every week. And that was a goal that she helped me set. I had to do it, because I promised her I would do it. And so now I make it to most of the meetings. Once in a while, I told them I wouldn't use it, but once in a while I use the phone. I told them if there was someone else in the congregation who needed it, but there hasn't been anyone else who needs it, so I just have it. Like Mondays are hard for me cause I go to dialysis, and at one time I was going to therapy after dialysis, and then going to the meeting made it really hard. And so I still use it, but, um, I am able to get there, and I'm tired, but I'll be tired here at home anyways so I try to go. You know, I think that's one thing that most of us find in dialysis is that you're tired a lot, you know? And the achy feeling, you know. So I go to therapy, in fact, I was supposed to go today, I still might go after I have my bath and everything, but if not I'll start next week.

Would you like to take a break and greet whoever just came in?

Yes, that'll be my husband.

It used to be that people would come in with you to dialysis. I mean, friends would come in, family could come in. I wasn't overly fond of that, though, cause I felt, I've always felt like your having a treatment, and when your having a treatment you don't have friends in. You know, if the doctor happens to come in, you gotta ask them would they step out, you know. I always felt like, you're only there 4 hours, you know, not like you're there forever. They could visit at your home. Maybe it did help some of them, having someone there, maybe it did help them.

You mean to help them pass the time?

Well, you know I like to read. I don't read like I used to since I had my last surgery, but you know, I was sitting next to Velvet, and Velvet says to me "you didn't read that whole book" and I said yeah cause for 4 hours I'd read and she said "you mean" and I says "yeah", and you know cause I can also watch TV a little, too. My whole family likes to read. All of them, my husband, kids, everybody. Always keep something in the bathroom to read (hahaha). And so that would pass a lot of the time. And 'course I like to talk. (hahaha). Not so easy to do, now, with who I'm sitting next to. But there was a time, you know, when I could, you know, sit next to somebody who really liked to talk. But I find, you know, that I was always able to go to one of the supervisors, to.... what was his name? What was it he did? You know who I mean.

Harold? The financial director?

OK, I always felt that I could go to him if there was a problem. And usually what I would try to do was, if there was a problem that really concerned me, I would try to go down a step further, you know, and then go up to him. And, um, I just never seemed to have a problem. In fact, when Harold left, 2 people came to me and said he was sorry he couldn't say goodbye. And I liked that cause I liked him a lot. I didn't realize until he was gone away that he'd had his health problems. He was nice, I liked him because he was new to the area, felt like he was new, and we were all new, too. Um, would you like to know something about the people there, you know, the caregivers?

Sure. I imagine that makes a difference in how the hemodialysis treatments themselves affect you.

It does. Sometimes you got some that are very understanding, and they do realize that it isn't easy for you. And then you got some that doesn't have the compassion, and I find mostly its the techs, I think mostly because the techs have-not gone through the training, the sensitivity training, and they don't have the nurse's training, either. People think that its just good enough to know how to fix the machines, and you know, set up the machines, and stick you. But you know, its a lot more to it than that, and I don't think they're given that training. So that concerns me, even now. Not for myself, so much, cause I've gotten used to it, you know, but for the others, you know, some of the things that they don't do, that I know if they had been through a training and doing it, they would. But it's things that they don't realize. I guess I think when you're working with people, you need to be trained how to work with people rather than just how to work the machines.

You implied earlier that your treatment sessions are different now than when you first started on hemodialysis. Can you elaborate a little on the difference?

Well, you know I get along with everybody. You never hear me complain about anybody, you never hear me fighting with anybody, I don't care who it is. So I don't have a problem, but a lot of the patients do. Now what I did appreciate is when we had more RNs, I almost cried when a lot of them left, because there was Mary, I could always go to Mary, I could always go to Denise. I could always go to, well to Deb I could, but she wasn't my first priority. You know, if there was something I really-and John, oh, John was always there and he knew a lot. And so when all of them were gone, and Jessica, she was there, and Jessica, she trained me in PD. I was real close to Jessica, you know, because of that and Jessica didn't have any kids when I started, so I kinda grew along with that, and there was just some comfort there that was lost. When all of them were gone. But now I'm finding that, well, like you, and I'm not saying this because you're here, you and Suzanne are very intelligent, and you know a lot about a lot of things, and that gives me comfort. Because I didn't feel that a lot of the other RNs knew a lot about dialysis. You know, we've got, um, techs or, like and LPN that we had over at the hospital, and she knows a lot about it. That helps you a lot, too, you know, you feel more comfortable. Course I was there when they were new, a lot of the new people don't know anything about that. They're comfortable, you know, but ...

You have confidence, then, in staff you feel are more knowledgeable?

Yes, yes, yes-yes-yes. (hahaha) You don't have to transcript it all, but, you know what, like I always ask question, like I asked John, you know, I asked him "John, you know I still got my kidneys that have failed. What are they doing now, lying dormant there or what" and he didn't have an answer for me. I wanted to know that! What could they be doing there, could be not doing anything, or rotting away or what. You know, so I like to know things. Mary was gonna teach me how to do the machine, I don't wanna poke myself with needles, but I wanna know why that machine is beeping, what's going on when its beeping, or when the window's not closed, I just learned that one. It's still making that noise because the window's not closed. And I like to know that stuff. I really do, it's just fascinating to me. And I, you know, I just like to know that stuff. But, um, I like helping new people. And if you notice, I usually, I stop by and talk to everybody, you know, just to say "See ya, Charles", or I stop and talk to the lady down on the end, Eleanor. I used to talk to the other lady, Rose, before she passed. And I holler "bye, north side", or "bye, south

side", I talk to everybody over there, cause, I don't know, I just kinda want to brighten up their day. I come in in the morning, I say "hello everybody" when I come. Rose, that died, you know, the first Rose, she says to me "I'm gonna start calling you sunshine, cause you come in every day with a smile."

You do.

I am actually happy. I don't have any reason to be sad. I miss traveling, and I miss shopping, cause I was in Tupperware, and in Tupperware, there was 3 times a year we went shopping. We went on a trip. And being Jehovah's Witnesses, 3 times a year we went on a convention. I don't do that now, so I miss all that, um, all that. And so what I do is I don't look at sale papers. You know. And um, but I am actually happy. There's only one time, only one time I've not wanted to come to dialysis. When my mother died at quarter to five, just before I left for dialysis, and I didn't really want to come, and I called John and told him I'd be in later and he said "fine". And then I thought, you're just gonna sit here all day and worry about having to go, so I called him back and said "I'll be in" and I went in an hour late.

I think I remember that.

You had just started. You were probably just starting out there. And I was on the other side. Um, I'm just happy. I am so thrilled to have dialysis. Because if I didn't have dialysis, you know, like I'm always teasing Sarah, it was a holiday weekend and she says "I'm not coming in, I'm not coming in" and I says "you are too" she says "No I'm not". I says "If you don't wanna come, don't come. But Tuesday I'm gonna put on my nice little black dress". She says "For what?" I says "To come to your funeral, because if you don't come you won't be here". She says, "Oh, I'll be there", I says "OK then".

Tell me about that, what is it like to have that hanging over your head? Or don't you think about it?

Oh, no. The only time I think about it is in the mornings sometimes I think, boy, it sure would be nice to sleep in, but then I think, well you can sleep there. I'm up all night, up till about 1 or 2 o'clock. So the little teeny tiny sleep I get before I go I should be able to sleep the whole time I'm there. But I've gotten in the habit now, that about 2 o'clock, I go to sleep, a lot of times. But it's not a threat, not a threat. Just something you gotta do. I think in the beginning it might have been. It might have been. I think at one time, one of the nurses was like, "I don't know how you do it, don't know if I could do it, its like a part time job but you don't get paid". I says "But we do get paid, we get life!" You know, so I guess I look at it like that. If I go there, I get life. If I don't, I die. And, you know, you see, I don't ever have a fear that I won't make it there, I just feel like, you're gonna go. It's not like you're gonna lose your ride, your electricity's gonna go out, what we gonna do? You know, I don't think of that. You just goin! I gotta, my husband takes me, all 4 of my girls got cars, my sister-in-law, my sister, and friends, they say "you just let me know when you need me", and I would never think to call. But my girls, once in a while, take me. I got no fear of not being there. Cause I'm going to be there! You know, what reason could I not....you know, I went out of town a couple of times and dialyzed out of town. So, you know, I don't have, maybe there's a reason I don't have that fear.

You did talk about your religion being such a source of strength for you.

Yeah, that may be. But what reason wouldn't I be there? That I wouldn't go? I do fear, sometimes, that I've had a little too much potassium. But I've done that only one time in over nine years, had too much potassium. Now I know what to do, is, if I have spaghetti today, and its on a Wednesday, well Thursday I'm sure not gonna be eating banana pudding (hahaha). So that's the way I do it. Or if I happen to eat french fries that haven't been soaked, then definitely, I'm not eating anything that's high in potassium until my next dialysis. So I eat all of the chili, soups, any of that that I want, the only thing I don't eat any of is oranges. Well, once in a while I might eat half an orange. And my husband, he loves bananas, so I'll ask him if I eat a bite of banana will he eat the rest? But potatoes is my favorite vegetable. And I eat those things, I do. You know, I hear the patients say "we can't have this, we can't have that", and I eat canned tomato soup and grilled cheese sandwiches. I love it. But I'll eat it on a Wednesday, maybe when I come

home from dialysis, and you better believe, I don't eat the whole can! And Thursday, I'm real careful. Now yesterday I didn't have anything high in potassium, so today I could probably have something. That's the way I do that. I'm real careful about that, cause there was this one time I did get a overload. On a Wednesday, I had spaghetti, Thursday morning I had spaghetti again, and in the afternoon, and Thursday evening I had potatoes that I didn't soak. I paid for it. And I said never again. The ER nurse, she says "I never seen you in here", and I says "and you never will again for this". I was so sick, I went to the Emergency, and they gave me glucose, did you know they give you glucose? They give it to you fast, or slow, or something, and oh, my hand swole up, it was awful. I was so sick, never, never again. Before I got sick, I didn't know nothing about dialysis, nothing at all. I'd never met anybody who had ever been on dialysis. I didn't know anybody, and I think, maybe if I had, that would have helped me, maybe. If I got with them and they said, "Well, I got like this because I didn't do this" or "I didn't pay attention to this", you know. So that's why I feel guilty. Dialysis don't bother me. I don't think about things I can't control. Like a lot of times people will ask me how I feel because my mom didn't raise me? Oh, I'm sure it was her loss, and it may have been a loss to me, too. But I loved her dearly. My kids would even say to me "Mom, aren't you upset she didn't raise you?" That's the past, you know, you can't worry about what happened in the past that you can't do anything about. And that's the way I feel about being on hemo. You know, it's something that I did and I know that there's nothing that will make me believe any differently. That if I hadda taken better care of myself, that I may have been on dialysis, but not as soon. Even today I realize that if you can keep your blood sugar close to normal as possible, then you don't have to worry so much about this stuff, you know, your eyes, and your feet, your kidneys, heart, all those things. I know that now, but I didn't know that then.

You were never told of these complications of diabetes and high blood pressure?

Oh yeah! I was told! I never believed. I never had anybody say it would happen, just it could happen (hahaha). And it wouldn't happen to me, you know? I knew it was something that could happen, but you got a lot of time yet. It had only been 30 years since I been on insulin. (hahahaha). So I was stupid enough to think because I was taking my insulin, that takes care of it. I was taking it, but I wasn't taking it like I should, you know? You know, recently, in the last few weeks, I been talking to a nurse, a diabetic nurse, and she sent me information that has really helped me a lot. I knew, but I didn't believe, I think that's what it is. I just didn't believe. That it would happen to me. But you know, I think I tried to push it to the back of my mind, cause that year before, when I told you I started this new job, I worked 80 hours of training, cause I was working in a group home. In the training I got a pamphlet that said when your feet swell, sometimes it could be kidney trouble. I ignored that. And I wonder why I did because my feet were swelling really bad. But that's not it, I remember thinking that, that's not it. But I was taken off of my feet, cause I didn't know being tired was part of the diagnosis. I had to stop driving. My husband would take me to work and pick me up. I was still doing Tupperware. I was a manager, and the managers got vans. But I just wasn't doing a lot. Just the bare minimum. Like I said, I really did not know. Didn't want to know. I guess. So that's the reason I blame myself for it. But I don't sit back here and cry boo-hoo-hoo. No way.

Sounds like you were in denial.

I think where the denial came in was, OK, you've got a disease, right? You feel like you've always felt, you don't feel any different. So you don't know what's going on. You don't think anything's going on just cause the doctor said it. You know, I would always think if you had kidney problems you would have a back problem. And my back didn't hurt. And I drank a lot of water. Being a diabetic, I guess. So I never had a kidney infection, never had a bladder infection. So I just figured nothing's going wrong. That's just actually how I felt. That nothing was going on. And after I came into the hospital, they did a EKG and found out that I had had a heart attack at some time before, but to this day I don't know when. Each EKG I've had since then has always shown that. I guess there were worse things going on that I didn't know anything about. And my eye exams were always good, I'd go and Dr. Kinzinger would say "Oh, fine, just as good as they were last year". He's say oh you're doing OK. You know, the only medications I was taking at that time was my blood pressure medicine, when I felt like it, and my insulin, when I wanted to,

you know. You'd think I was so uneducated. But it was just, you know, I didn't think it could happen to me.

You talked about when you first got diagnosed, and you were still worried because you didn't have insurance. How did you ever resolve those financial concerns?

We had, uh, a Social Worker, name was Sherri. Sherri came to me within a couple of days when I was at the hospital. She told me that I could probably get Medicaid, but definitely I would get Medicare. Everybody on dialysis automatically got Medicare. And Patty told me later they went to fight for that. I can remember just like yesterday, one of the brothers from the congregation, he came in, and I told him how good I felt because I could get that. And that was my biggest worry in that whole year. You see, I took this job because I wanted a physical and I wanted insurance. I could make more money selling Tupperware than I did working there for 8 hours. I could hold a party in 3 hours and make more money. And so I wasn't working there for the money, cause at times I'd have 2, 3 checks I hadn't cashed yet. Because I wasn't working there for the money. I was working there for the medical insurance because I knew I was sick. I knew if I went to the doctor, they'd start with all kinds of tests. Because a few years before that, I went and I had a tumor, and I had to have a hysterectomy. And I had to pay quite a bit of money down, cause I didn't have insurance, I had to pay the doctor in advance, I had to pay the hospital in advance, it took me months and months to finish paying them. It was hard! And I knew that's what would happen this time, too. Soon as I said I didn't feel good, they'd start saying "Let's have this test, let's have that test", you know? So that's why I didn't go, and I was struggling to get insurance. I got the job, but they didn't put me on for a long time. I got full time, but she said "I'm sorry, we can't put anybody else on insurance". And we didn't have a union, they did whatever they wanted. So I never did get the insurance. Although I got the full time hours. And this is something that, let me see if I can make you understand this. We believe that our 1st responsibility is to Jehovah. We believe our responsibility is to go to the meetings. Scripture says seek the kingdom first. That's how it is, and everything else will fall into place. I stopped going to the meetings, cause I was working nights. And I told her when I took the job, I told her I would not be able to work on Tuesday or Thursday nights, she says "OK, fine". I got the job. But then, it was, "can you come in because so-and-so called in" or "can you come in for this", you know. And I stopped going to the meetings. And that was my biggest guilt. That I was missing meetings, I wasn't getting the spiritual food I needed. And I still didn't get the insurance. And after all that, I was able to go into the hospital and get Medicaid and Medicare. So Jehovah provided for me anyway! Which he would have done anyway. And maybe if I had not taken that job, I might have had more faith. Apparently I didn't have enough faith, I didn't think Jehovah would take care of me. You know, I felt I had to do it. I believe now, that, regardless of whatever happens, if I do the right thing, its gonna come out right if it's his will. Is that confusing to you?

No.

Because that also was a guilt to me. Is that I missed so many meetings. And we go through, on book day, on Monday nights, we go through a book. Like now, the book we're going through is *The Greatest Man Who Ever Lived*, we go through a few pages every week. And I missed a couple of books. So that was a lot of guilt, a lot of guilt. Cause I missed all those meetings for a whole year, and I still didn't get what I wanted to get, you know. I'm not able to make decisions for myself, you know, in going against what the bible tells you. So all of those things really helped me, you know..dialysis helped me because I really had a problem and He was there to help me. All that year I was worried, thinking, "oh, you got enough faith", but I wouldn't be missing meetings to make money I didn't even want. Oh, I could use the money, but the money wasn't the object. I didn't care, I just wanted to get insurance! Sometimes I'd have 2-3 checks I hadn't even cashed, just sitting around. But I was so tired, I'd get paid on Wednesdays and I'd be too tired to even go cash the checks. It was pitiful, pitiful. But I got a lot more energy now. My husband does all the laundry, I don't go up and down stairs. A few years ago....I don't know if you were there, Molly, were you there when Kim was there?

Yes.

No, it was more like 5-6 years ago, you weren't there yet. Anyway, I had this attack on dialysis and started to vomit, and my stomach was hurting real bad. And I got off...you remember Pat? She was the first black tech they ever had. Sweet girl. And all of them came over, they were so good to me, the nurses, so good, Kim and Pat, and Karen. And I told them I had to go home, and so they took me off. And I went home. As I left Pat says to me "now if you don't feel any better you just get right over to Emergency". I says "I'll be OK". I got home and turned right around and went back out there to Emergency and I had gangrene colon! It was on a Friday, and they did everything over the weekend trying to find out what was going on, so Monday, which was Labor Day, they did emergency surgery. And that's when they found out what it was. Then, it's the funniest thing, I hadn't been sick since before then, and the nurse, even then, she says "I been here 30 years and I've never seen you". But I been on dialysis 4 years, but I ain't never been sick. I tell everybody it's because I don't take blood. I refuse blood. And I mean I needed it when I first started. The doctors were so good to me. They were so good because, I just told them I didn't take blood and they just gave me all kinds of EPO (hahaha), I think 10,000, it was, and I would take it in my arm, or my stomach because they wouldn't give it to me in the machine because it works better in a shot. At that time it burned, because they didn't add anything in it, and it was painful. Now all through my run, all I could think of, was at the end of my run I'd have to take that shot. I was just afraid of that shot, but I knew I had to have it. And they were really good, they didn't try to encourage me to take the blood, or anything. And they gave it to you at the end, last thing, even after you were off the machine. That I had to live with. But they were real good to me about it. They never tried to encourage me at all. And so I haven't been in the hospital at all except for that and the hernia repair, nothing related to dialysis.

You've tried 2 of the 3 current treatment options for kidney failure, PD and hemodialysis. Did your religious beliefs, that is, not taking blood products, did that keep you from pursuing a transplant?

At the first 2 years, I didn't think I wanted it. I didn't think I wanted a transplant. I had had so many surgeries in my life that I never wanted to have surgery again. And then I don't know if you remember Mr. Jimmy Frazier. He got a transplant from one of his family, and then I thought, oh that would be nice! He was gonna drive down south, goin visiting, and he came back looking so good, so fat. Then they were supposed to send me to St. Mary's, and they rejected me. And also, Beaumont did. Because of being a high risk, having had a heart attack, my circulation, which if they did it they said that they'd have to do some kind of 'gram, first. And of course not taking blood. They can do the surgery without blood, at Beaumont, because it's considered a high risk hospital. But they wouldn't for me because of the other things I had wrong with me too.

Was that a big letdown for you?

No. No. It wasn't a big letdown for me because it was never a priority. Until after I saw him. In fact, I went over there by myself and he and his wife was "you shouldn't be over here by yourself, you should have somebody over here to help you", and this and that, and you know. But no, it was not a big letdown. I don't even know if I did a lot of talking to my family about it. Because like I said, it was never a priority. Probably if I had wanted one right from the beginning, I might have been put off. But I didn't know anything about dialysis. I didn't know anybody that had been on dialysis, and, you know, I think there was, in fact I talked to Dr. Twu about it, and Dr. Twu said to me because of your age, and the quality of you life, I would say yes for a transplant. Now that was right away, right within the first year. But I definitely would not ask anybody to give me a kidney. No way. I just wouldn't, it would just be something I just wouldn't ask anybody to do. And, I had a daughter that was diabetic, so she couldn't. And my other daughter had been exposed to hepatitis B, or C, or one of them. So she couldn't do it. And my other 2 daughters smoked. They couldn't do it. I just wouldn't have asked my sister to do it. And then I didn't think I wanted someone else's organ in my body! You know, I wondered how you feel with that, you know? But it didn't have anything to do with religion. Because that's a conscience matter. Some people would feel that they don't want it. Because of our religion. But I don't think I'd feel that way. It's a conscience matter, it isn't something that the Bible definitely says, like in the Bible it tells you not to eat blood, that's the scripture we use, you know, for blood transfusions. Then we could be blamed for eating blood. I

couldn't take blood that had been outside of my body. I think of the tubing that we use, not as outside of my body but as a continuation of my body. So that's the "conscience". What I do, a lot of them wouldn't do it for that reason. Cause before I ever got on hemo, I always thought that I would because I thought "that's not right"....and the doctors would ask me "can you save your own blood". Once the blood has been out of your body, no, you can't do that. So that's the way they feel like. And hemo, the blood's out of your body. Or that's a continuation of your body with the tubes. If that's the way you want to look at it. That's the way I look at it. But the transplant, it was never a priority. I think I was so disappointed that I was, um, had ruined my body, and I think of all the years I was gonna lose weight, gonna lose weight, gonna lose weight, and never did. Now I've learned to live with this. It's been almost 10 years, and it just makes me feel, well, who's to say it couldn't be another 10? But if it isn't, 10 years has been a long time on dialysis. I've seen so many people come and go there. That I've been really fond of. Remember Shirley Friend?

No.

Oh, you missed out. They used to put her on the machine and she'd cuss everybody out. She used to sit over in the corner there, by the isolation room? She'd put her own needles in when she felt like it. And she took them out when she felt like it, too! (hahaha). You know, in the beginning, I always thought I could not stand it, could not stand it, those needles. But it hasn't been so bad. It's painful sometimes, I sometimes had to have 4 needles, 3 on one side and one here. And Dr. Petty is always complaining about not going up further. So I told them they had to go up further with the needles. Poor Dave, he wasn't able to get it in, it looked real good and felt real good, but it kept "drawin", I guess. Anyway, it wasn't working. So he had to try to get Jackie to help him. They eventually had to take it out, and she tried all over again. Nothing, they had to go back into another spot they hadn't used before. But, it wasn't the end of the world, and I didn't get mad with them, you know, you don't get mad at the person that's trying to do it, I knew they weren't trying to hurt me, they were doing the best they can. And I knew they felt as bad for me as I did. It's not as bad as if you as when I started. That was one of the reasons I didn't want hemo. I just didn't think I could stand that big sewing-machine needle! And, um, a lot of people are upset 'cause they got all these big ol'' scars, but that don't bother me. Maybe 20 years ago it might have bothered me. You know, more vanity. I don't know, I really don't know. See, my thing has always been, I always put everybody first. My family first, all my kids first. You know, I always felt that the kids had to come first. Like I said, I didn't think I should work if I didn't keep the house clean, cook the meals, keep the laundry up. Ol'' Miss Do-It-All, Supermom, that was me. So I wouldn't think the scarring would have bothered me even when I was younger, in fact, my grandmother used to tell me she hoped I wouldn't be like some people, wait until I was old and then start running around. I've never been one to go out and do a lot of partying. So it couldn't stop me from working! Work-work-work-work-work!

I wanted to ask you, when you were talking about your PD training, you mentioned your husband having a drinking problem at that time. Were you implying that might have been influenced by your health problems?

Say it again?

Did he have that problem before you began having health problems? Can you describe a little more how your family dealt with your illness?

Oh, yes. Yes. Oh, yes. But not as bad. And the rest of the family, they ignored it. They ignored it. They didn't think... Mom has always been there, see, even when I sold Tupperware, they didn't think it was any job. They said "Mom's got a real job now" when I started working at the home, because they could call and I would be there. They could say "can the kids come over", even though I'm working with my Tupperware, doing this or doing that, working on the telephone doing my orders, they still would not think I was working, cause I wasn't away from home. So, Mom's never been sick, and we can just ignore it. No, no. She's, unh-unh, no. I have one daughter, she cannot, she does not face anything. Laurie. And my daughter that just called, she, I was telling her what they were going to do when they do my surgery, and she says

“OK, Mom”, she can’t stand to hear stuff like that. Like when my mother had surgery, they told us to come into the room and talk to the doctor, she says “can I go?” But she came, and she almost passed out when he went to tell us what he did! So, they kind of push things away. But, you know, I do think it bothered them that Mom’s not Mom. Cause I’ve always been the strong one, always been the one to make the decisions, say you can or you can’t. And I was always the one, if I said I was going to do something, I did it. If I promised them something, I did it. And they knew if they needed something, you know, I’d be right there to help figure out how to get it. That, I think, bothered them. It’s hard...That’s one of the things about being a diabetic....like I have one girlfriend, her daughter would say “Mom, did you take your insulin?” Nobody has ever, ever, at any time said to me did you take your insulin. But see, for one thing, my kids were adults by the time I got on dialysis. And most of my diabetic years they were adults. See, because my oldest daughter is 40. And my youngest daughter is 34, I believe. So they weren’t just little kids affected by Mommy’s illness. They weren’t living in the house. You know, not having little kids at home. that made a difference. I went to a seminar in Kalamazoo, Your Children and You and Hemodialysis. And it was very interesting, but it didn’t mean a lot to me, cause my kids were not little. The Kidney Foundation put it on. They have them all the time, in Kalamazoo. I first got on hemo, I went. And they send me papers and things, they were very, very interesting. And I went, and I think there might have been a film, too, and people talking. And it was very good for people who had little kids. Cause it helped you to explain to them what’s going on, you know, to help them. In fact, they’ve got a coloring book, too. For kids, and this one lady, I can’t remember who she is, I went to a seminar here, too, in Muskegon, that the Kidney Foundation put on, it was Roy, and Velvet, Greg, and several more of us went. Anybody could go, and we decided we wanted to go and we went, for about six weeks, I guess. And oh, did they feed us good! I mean steak, whoooo, and all that. Good food. We learned an awful lot there. He explained about the money situation, how the government doesn’t give them enough money for dialyzing, and things like that. That’s where I learned that they have a coloring book. And this lady, she gives them to people for their school!. They have a program for the kids to learn about kidneys. Functions and kidney disease. I thought that was pretty neat, because so many people are going on dialysis now. My grandson was really little at the time, and I could just remember him saying “Grammy, what dimamalys?” (hahahaha) What’s dimamalys, he would want to know. Come to think of it, he was born after I was on dialysis. So things have just progressed along. I’m not able to do some things, like when my daughter had the baby I wasn’t able to go help her. You know, we should wrap up. I should get to therapy. I’ve pretty much said all I can think of.

I sure appreciate your insights, and your sharing them with me. I will be calling within 2 days in case you want to clarify anything or add anything. Or you can call me anytime.

Co-participant # 02010171

Well, in about 1994, I started to have problems with my kidneys...you know, feeling logy, and all the other symptoms of kidney failure. So when that happened, I went over to Grand Rapids and had, well, it was actually one of my cousins' husbands, a cardiologist. So I asked him what should I do? And he said that he had a friend that he went to school with in Grand Rapids who was a nephrologist, and that he's good, he's really good. So he said I should contact him, and well, I contacted him but he was retired. And they gave me another guy. And he started working with me. And so in 1994 till 1996, I battled this thing, as far as not going to dialysis. I didn't want to be tied to a machine, and my job involved so much traveling, you know, that's kind of tough. I just didn't want to do it. I fought it and fought it and fought it. I had some real bad days. I was taking lots of medication, things like that to keep me out. But my diet, I actually really stiffened up my diet, you know, the nephrology diet. It's odd we were able to fight this thing off until August of 1996. Well then I had a, well I ended up with a colostomy, emergency surgery and a colostomy. That was here in Muskegon, and, um, I wore that bag until, um, well that was in February that they did the colostomy, that was until August of 1996. Well, we made arrangements to go up to Mayo's to reverse the colostomy the end of August in '96. Once I got there, they wouldn't touch me until I had gotten on dialysis. The doctor told me that my body just was not in shape to take on an operation, and unless we do it, then you've got some real problems unless you go on dialysis. So August 16th of '96 they put me on dialysis.

At Mayo's?

Yes, at Mayo's. And they dialyzed me for 2 weeks before they'd touch me. So, I just stayed there and dialyzed. Got my blood cleaned up, and then they went ahead and did the reversal. So then in order to get back to Muskegon, we arranged to come to West Michigan Center, or they did. I had, I had talked to the West Michigan nephrologists before that, anyway, I knew who they were, so I said okay, let's do it. So we transferred back. Then I had to work out how I was going to, what I was going to do about keeping my job. This was 1996. I mean, I wasn't ready to retire yet! And so I did, we came back to the routine, 3 times a week, things like that. But I worked out a deal. I actually bought the catalogue for traveling from the government. Whenever I had an assignment and I had to travel, I'd go ahead and line up all the necessary paperwork and everything else. I could see that our clinic wasn't really used to having people travel a lot. And so I did it myself. Contacted the clinics, what I'd actually do is find out where my assignment was and, um, a meeting someplace, or a convention, or something like that or an engineering meeting, I would ask, find out where it was, find out where the hotel was, on my computer. On one of those streetfinders. Then I'd pull out my clinic book and look for clinics in that city. Or I would find clinics in nearby cities to where the convention was. Maybe there would be 4 clinics or 5 clinics. I would plot them all on the computer, and I'd take the first one first, I mean the closest one first. Locate them and call them up and see if they had an open chair on the days that I needed it. I would have to work it in with my meetings, when my meetings would be. And I'd find out when, and where they are, and if they had an open chair on the days that I was free, or around the meetings so I could get in and get back out. Six in the morning, and things like that. Or after the meeting closed. If the meeting closed at four, or something like that, then I could get a chair at 4 or 5 in the evening. I was all set. So, but if they couldn't take me at the closest one, then I'd call the next one. And I'd get that pinned down.

You sound as if that was a lot of work and hassle.

It is. And then when I get that done, when I get those people to say "yeah, we've got an open spot for you", someone just died, or, well, anyway, then I would get our social worker, uh, to communicate with those people. And that really worked out okay. They just send my last flowsheets, and I actually carry my last flowsheet, and uh, they get it all set. They get it set with your insurance company, uh, I guess to make sure they get paid. That's worked out pretty darn well. It took a lot of hassle, you know, to do it. But I got to keep my job. You know, I wanted to do it well, and to continue to, you know, get dialyzed. It's just a shame that too many people are afraid to travel. A lot of our people haven't traveled. And, um, I met one young woman out in California who's been on dialysis 16 years, and she'd never traveled. And it's a

shame, you know, she's a young woman. But the main thing is you've got to adapt to your situation, it's going to be there, it's part of life, and you just, you just roll it right into your life. That's what it is. And accept it from a positive point of view. Then it's a matter of adapting your attitude. This is life, this is real. And you'd better accept it as such and integrate it into your lifestyle, because it's not going to change. And then this travel thing is, it's really important, because you've got to realize you can travel, and people are scared of the unknown. And so, it's just a matter of integrating it into your life and, I'm working on the GAMBRO situation, which is a great deal, because if you travel within the GAMBRO circuit, and go just to the GAMBRO clinics, they just transfer you to the clinics on the computer.

Oh, so you don't have the insurance hassle, and all that?

Uhn-uhn. Because they take care of you, um, if you're insured at this clinic, they know you'll be insured at that clinic, so you become, they transfer your records over there, on the computer. I've been to Colorado, to Denver, and they transferred me in the computer there. And then to Florida, for, um, we were down there 5 days. And that worked out great. And so what I'm doing is, I just got a list, I had them print it out, I got ahold of the people down in Tennessee, the U.S. headquarters for GAMBRO, and they sent me, well, hold on, I'll go get it.....See, there's a typical program. I checked out these different clinics until I found the right one, the one I'm going to dialyze in, and then I look up....She was going to try to charge me over \$6000! It was stupid. It was in Boulder, the one I went to before. They've got a new owner, and they really screwed it up. They couldn't communicate with BlueCross/BlueShield for some reason, and our clinic supposedly didn't tell them what they wanted to know...bunch of bullshit. So the end result was that I just said the hell with it. And then I got into the GAMBRO system and went to a GAMBRO clinic. I had to drive to Denver but no hassle whatsoever. The thing was, in Denver, I knew how to get there then. Actually come down Colorado Boulevard. It really worked out well. I've been to 5 different clinics in Chicago. They're all in some kind of medical group, so it works out great. I just go wherever they've got space in the 5 clinics. I have meetings in Chicago a lot, but we usually stay at the Holiday Inn in O'Hare, you know. There's a lot of meetings there. Some of the clinics are only a few blocks away. It works out well.

You could walk to them.

I did that in, where the heck was that, oh, Atlanta. Down in Georgia I was only a few blocks away from the clinic. From the hotel. That was great. But anyway, this book, it's not organized by state. It would be a lot easier to use if it was organized by state. But it's organized by the clinic names. So that's what I'm doing, is organizing it by state. She was going to go through, this Gina, she was going to go through and pull everything in Maine and Massachusetts. You can see the work she'd have to do. And she said "If you want all the addresses I'll give it to you in 10 minutes." And I've got a fax machine here, and I said "fax 'em off". So I'll take this from here and see what we can do about getting them sorted and make them available. Crystal, the social worker, wants a copy of it, so I'll take that in today and give her a better copy of it. But that's the program at this point. And my feeling, is, um, trying to be an advocate for a better life, you know, for dialysis patients. And a lot of them just don't have the get up and go, or the contacts, or, or, it seems that people are so afraid of going someplace, and with my experience, I've been in 29 different clinics now, and I've never found a bad one. The worst one I found is, as far as conditions were concerned, was in Cleveland, right there at the hospital, just like this one is. But it was an old building, and, um, the equipment was all right, and it was clean, it was just an old, run-down building. I've been in some brand new ones. This one I was in had actually just opened, and Medicare hadn't even approved them yet. But they had been approved by the state. They had 16 chairs and 6 patients! So we got great treatment there!

Talk about individual attention!

They even stayed over one time, I mean they didn't have any patients on second shift, at 12:00. And they stayed for me. So it was great, wonderful. They had a good crew. I guess then you'd be going back to the concept of your life. I mean, you've got to look at it, if you don't do it, you die! It's that simple. If you

want quality of life, then you better do it and do it right. As well as your diet. You know, the importance of the diet. And you better stick with it. You know, you can't go out boozing, and all that jazz. Cause it's tough, I mean you can, but it's going to be hard on you. You'll have a lot of cramps. That's what happens. I guess my biggest concern is how I got there. The fact that, the damn moral of it is, um, too much of the wrong kind of antibiotic. I had a staph infection in my leg when I was presenting a paper up in Toronto, Canada, and cut my foot. Just a little slash. Then, uh, it started to hurt, and I thought it was just muscular, so I put it in a whirlpool. Bad mistake. Bad mistake. Boy, the next day that thing started growing, had a terrible staph infection. By the time I got home I couldn't even put my shoe on. And my leg was swollen up, and I went down to my doctor. And he wasn't there, he had somebody subbing for him, the guy was a jerk. Boy he slapped the antibiotics to me, and cured the problem. But 6 months later, when I had the kidney problems, so I swear, it's the only thing I can pin it to. Now I wouldn't have known that could have done it, except that when I was up at Mayo with that pseudomonas infection here, uh, I was sent there by, um, what's his name, the guy that's a hot-shot on different types of bugs...

Dr. Olsen?

Yeah, Dr. Olsen. Yeah, that's him. He says, boy, I don't know what it is, exactly. So Virgie got, she slapped my butt on an airplane and flew me up to Mayo's. And I think Olsen was happy that I was going. And they told me up there that there are about 4 types of pseudomonas, but they're all bad bugs. I figured out, their almost like that flesh-eating bug, you know? Cause that hole got bigger and bigger, and it was only just an itty-bitty scrape. What I got it from my grandson, they were staying here with us, and we were playing around, and he just nicked my chin. That's all it was, and that thing started getting bigger and bigger, till it was almost the size of a nickel. And so they slapped me into the operating room at two o'clock in the morning. This young kid from, um, from Wayne State, he was there and he slapped me in that chair and turned me almost upside down to get at it. And he cut this all out, and inside, he cut it in here too. Cut that all out. You know, it was a tough thing. They said well, it didn't get to the bone. He said if it had got to the bone it would be pretty serious. He said it's serious, you know, but I think we got it. And then they put me in a room, you know, an isolation room. I said, this is bad stuff! What the heck is going on here? (pause to talk with wife)

I still work on dialysis and, ah, that was in June, or July, August. I think it was June.

So it was after the foot infection?

Yeah, after the foot thing. And they would come in and put on gowns and masks whenever they came in there. My nephrologist, I went through the nephrology department, she was my guru. Anyway, she said it was pretty contagious. So everybody had to wear masks, gowns, and gloves and stuff, you know, the rubber gloves. Then she explained it to me that there's antibiotics that are dangerous as far as your kidneys are concerned. And she explained to me that some of them would wipe them out. So they were careful about what antibiotics they gave me. I still wasn't on dialysis.

You knew at that time that your kidney function was going down?

Yeah, yep, yep. It was going down before I went up there. So then I switched to these guys, the nephrologists, I mean it was a lot handier then going to Grand Rapids. So that's where I got the insight, I mean, I'm pretty damn sure it was the antibiotics. Cause I had nothing else, see? I hadn't gotten into any environmental problems, had any exposures that would have caused it. And Virgie wasn't getting it. As far as our water is concerned, I mean, all I can trace it back to is this medication thing. In that study, I don't know if you've looked at it, that study of why we've had so many kidney problems in Western Michigan?

I saw part of it.

Yeah, I've got a copy of it here. I stashed it away. But, that was stupid. They didn't look at medication and they didn't look at environmental factors. It came out that kidney failure is caused by poor

socio-economic conditions. It's a bunch of bullshit. It pissed me off, and it's kind of racist, you know, the poor black people. Anyway, it's bullshit. Society, environmental conditions, I feel, it's caused by environmental conditions and/or medications. But I guess as far as this program is concerned, the most important thing is proper care. You know, and proper medication. That's why I'm happy that these guys do my whole health care. I have these 4 people. I do have Dr. Wright as my family doctor. We're firm believers in using vitamins and stuff like that to keep our bodies in shape. And it's helped. I guess we take a lot of stuff. But it works. That's one of the reasons I've got me in such good shape. I guess to sum it all up, it's mostly your own attitude. How you feel about making it through life and still maintaining high quality. Cause I have highs and lows just like everybody does. Now the docs at the center don't believe in vitamins. Well, they do somewhat, but I do what I feel is right, is working. And some of them, well, I've brought two new concepts to the clinic, and they're using one of them, but the other is for my PHN. My post-herpetic neuralgia. When I went through this colostomy thing, I got shingles and that crap that gets in your mouth...

Thrush?

Yeah, thrush. You know, its like hair growing in your mouth. Terrible, terrible, I was just miserable. My tongue was all fuzzy, the side of my face looked like it had pimples all over it. And then I had, we were going wet to dry on the open gashes where they'd done the replacement, or revision, and I mean they were about that deep in my stomach, and I was doing wet to dry, packing those things. And then I got infection in that, a little pocket of infection. We had the visiting nurse come. She was great. But boy, stuff like that just knocks you down. Your body's all cut up, got infection in it, that wet to dry, you know, every day, it was just miserable. So your attitude goes to hell then. And I still had the kidney problems. I wasn't on dialysis then, either. It was, oh, it was when I had the bag on me. I did the wet to dry myself. Packed it, take a long string of gauze you know and soak it, then pack that baby in there. Oh, and it hurt. And when you have to do it yourself, Virgie wouldn't do it, she said "no way am I gonna touch that", she couldn't even look at it let alone do it. As to starting dialysis, I was really concerned about it. Because of the entrapment. Your life is really different, and that was my major concern, I didn't want to be strapped to one of those machines. We'd been traveling a lot and just didn't want to get hung up. And I fought it and fought it, for years, from 1994 to 1996. And then one day, it was Thanksgiving in 1995, I didn't want to eat. That's something new for me (hahaha). I didn't feel like it, and I was logy as hell, I just wanted to lay in my big chair and to hell with it. But I really didn't know what it was all about. If I'd known then what I know now, I would have gone on dialysis. Cause I had a year of just misery. I was just tired and logy and just didn't feel like doing anything. I would have started dialysis earlier. That's a good point of people understanding the quality of life on dialysis. You can have quality of life. If you organize your business properly. I see a lot of people go completely disabled or take advantage of the system, getting income from the system, and so on. But I'm not like that, I couldn't do that. But I didn't want to be strapped to a machine, either. But it was a matter of once they forced me into it, you know, with the operation thing, that I realized this was the best thing I could do. And, my attitude on transplants, I really don't believe in them because, you know, they fail. Some guys have 2 or 3 separate kidneys, and then they go back on hemo. I say, hey, I know what it's like to fight this thing. And so on hemo I feel better and have better quality of life than these kidneys failing. Cause you know, you have to take this rejection drug, too. Which is bad news. I don't like prednisone, I hate it. I hate prednisone. It chews my skin up. And every time I bump something I bleed. I just hate prednisone. It's a great drug for doing what it's supposed to do, but it's terrible. You know, some people are on 10 mg, that's not bad, but I was on 60 mg. I was on that and cy-, cytoxin?

Yes.

It's a pretty good combination. I was on that routine, the doctors in Grand Rapids put me through it and brought me back. My creatinine went from 7 something down to 3.5. And 2.5, it's not too bad. But it gets up around 7, well, that creatinine is poison. It's poison. So they brought me out of it with the cytoxin and the predisone. I'd go over once a month to Grand Rapids, well, it was really in the cancer clinic. And I'd

spend all day there, with this stuff, this process. They'd put it in there and drain it out, flush it out and do some other things. And me sitting there with all the cancer patients.

That had to be a difficult atmosphere.

Yeah, it was something else. But I had to be there. And that took care of me back in '94. And then I really got in trouble in '95, we started again. But what happened is my creatinine went too high and so they, oh, I know what it was. I was on the program, I had just got started on the program, and felt better. Then in December of '95 I went back, and he said "Well, I can put you back on the cytoxin program" and so I so I started it. Then my potassium went way up, so I took 300 grams of Kayexalate. And I still think it blew my bottom out, cause I started bleeding rectally. I was on a business trip, and I bled in 3 different cities. And I stopped in Colorado, in fact was at my daughter's when I was taking the Kayexalate. I took too much at a time, I should have taken maybe half. But anyway, I went into the hospital there in Boulder, and they got it stopped. They scoped me and found the bleeding and, well, they probably burned it. And what's interesting is I guess where it was cauterized is okay, but it was someplace else that caused the problem, diverticulitis. And what I feel is that the Kayexalate kicked off the diverticulitis. Then I was on my way out to Portland, Oregon for a presentation and a show. I was meeting a guy out there. And I just got there and I started bleeding again. And so then they slapped me in a hospital out there. And they wanted to fix me up right then and there, do surgery and all. And I said no, I want to go home. And what's comical is our sales manager had a heart attack and they did a bypass on him out there in the same hospital I was in. So anyway, I came back home, and they got me stopped and everything. So I flew back home. And 2 days later I started bleeding again. So they slapped me in the hospital and did what they had to do. That's when I got the blockage that led me to the situation I'm in. And my wife, well, it tears her up. She thinks I'm going to die on her. Everytime I get out of dialysis I give her a call right away. Because she's afraid they might throw me in the hospital. That one time my temperature went way up and I went into the shakes they threw me in. And then this other time I had this bad heart thing, this fibrillation, and I only finished half of a run and they did that. They said they can't take a chance, they had to get my heart slowed down, so they jerked me out and they dialyzed me in the acute unit. I got dialyzed there twice, I was in there 2 1/2 or 3 days. It came back down again.

Your heart rate?

Yeah. And what was fun was, the nurse I had was from the kidney center. Barbie. I call her Barbie 1. You know we had so many Barbs at one time. Yeah, Barbie 1, Barbie 2, and Barbie 3 was at the desk. Barbie 2 is still over there with you. I guess, but I haven't seen her in a long time, maybe she's working on the North side with you?

No, she's actually working in the hospital full time, with Acute Dialysis.

Yeah, Barbie 1 is working on 2nd floor. It was great to see her. She used to give me all kinds of special care, you know? But anyway, that's what was happening. So poor Virgie was afraid that I'm not going to come out of there, you know? But that's because she doesn't realize what a good job you guys are doing. I tell her if something's going wrong with me, boy, they take care of me immediately! It isn't like calling my family doctor and seeing what he thinks. They just do it, you know, just do it. She's never been in to see the unit or the machines. I've tried to get her to come in, like the time I was in that new unit. There wasn't anybody there except myself, but she wouldn't do it. We were talked to together at the beginning by the doctors, told what to expect, and she was invited to tour the unit on a couple occasions. I guess we didn't get to the point where we were going to drag her in. They invited her, but she just didn't want to go in. Out in Boulder I had my grandson come in and spend time with me. A lot of units don't want the families to come in, but a lot of units don't mind. Some people have someone come in and sit with them, they stay there the whole 4 hours. I wouldn't want that.

I always see you with your laptop. Will you still bring it even though you're retiring?

Yeah, I've got to. I've got so much work to do now, on my book. Lately I've been so damned tired I haven't done anything. I just sleep. I'll sleep for, oh, 3 hours. I don't know why, maybe I'm just not getting enough sleep. Sleep deprived. Cause a lot of times I won't get out of work until 11 or 12 at night, and wake up at 6.

Has your energy level changed since you went on hemodialysis?

Yeah, yeah. It goes up and down. Based on how good a run I have. I'm also concerned, recently, about my energy level going down. Whenever I'm high on potassium, my legs get heavy. And Friday nights I worry, because everyone is in a hurry to get out of there. I have to prompt some of the people about getting my medication and when I'm supposed to have it. Like I have to have my heparin shut of at an hour and a quarter ahead instead of an hour, the norm. I have to remind them of it. And then I'm on that, um, Carni, what is it?

Carnitor or Carnitine?

Yeah, yeah, that's it. That stuff. I have to remind them of that. One Friday night they forgot all of it, my EPO, my iron, zemplar, and the other stuff. They ended up giving it to me all at the end. But I had to remind them. So that bothers me. And some of the transient people that are in there are somewhat careless sometimes. They aren't careful, they just want to get out of there. That bothers me. They just have to take the time and do it right, be more careful. I think Wanda has a good stabilizing effect around there. The old war horse, you know.

She has a calming effect?

Yeah. She makes sure it happens, gets done right. She gets upset with some of the people, they get careless and sloppy, and just don't think about what they're doing. They just do it mechanically. Instead of realizing, hey, this is a very important situation. And another thing, this is going back to the potassium thing, they were changing me from a K2 to a K3. And I'm not sure if that's doing the job properly. I wish sometimes that we could have potassium checked before and after dialysis, and see what the change was. Somebody said that you should come out consistently based on the bath. I guess I believe that even though the bath is consistent, that doesn't necessarily mean my potassium is brought down to the same level every time. I think that's where we get the variability in this potassium. I know I felt better on a K2 bath. With this K3, I can feel it in my legs. My legs get heavy, and my energy level is low. I have trouble right now, if I crawl down on the floor, I have trouble getting back up. That bothers me. And I'm weak at times. If I go down to the lake and then come back up, it takes some effort to do it.

That's not a little hill, is it?

No, it's about 32 feet down the stairs. And if I walk across unstable ground, I have to be real careful. Cause I could fall. I'm in a rehab class, a heart rehab class, under supervision. That's what I like about it. Cause I'm doing it and they step it up and do a great job of monitoring. What I've done is I just pay for it one class at a time. 5 dollars and a half, that's what they charge me. That's not bad. That forces me to do it under monitored conditions and it's a great program. I just tell them what I need and what's happening and they develop my exercises accordingly. So this energy thing bothers me cause I'm not sure where it's coming from. Maybe this heart medication. I don't know. I don't know how good these guys are, really, at heart. You know, the nephrologists. But I'm going to talk to whoever's there, Downer or Twu, they're pretty good, about this weakness, when I get down it's hard to get up, and this instability. Now when I go walking around around here, I take a walking stick with me. I don't like the idea of a cane or a walker. I just have a walking stick here. I just use that. It helps a lot, you can't believe the confidence it gives. But I'm getting away from the subject. Let me tell you about a typical dialysis session, as I see it. What I would tell someone who was going to start dialysis. Be there on time. A lot of times, the people are late getting on because the previous person dawdles, so be there on time. So that you can get in and get started.

And its a matter of getting your weight and your temperature, get that taken care of. Then if they've got the chair cleaned up and ready to go, you're all set. Then its a matter of finding out who's going to dialyze you, who's going to put you on. And, uh, just get ready, take in there what you want, like a lot of people take their lunch in, stuff like that. I hardly ever eat in the chair. But get in there and be ready to go. And take your gear with you, something you want to work with, a computer, like I'm writing stuff up, a portfolio there to work on, and dress comfortably, that's pretty important. I mean, you're laying there for 4 hours. And, then the other thing I did was develop my "chicken juice" (hahaha). I mean that helps a lot. A lot of those people are just scared shitless of those needles.

You mean the ethyl chloride spray you use to numb the skin?

Yeah. Those needles, man, I mean I've seen people scream and yell, I mean, it's traumatic. They just go crazy! I don't know why they don't use some spray or give her some lidocaine, or something. Some clinics actually give lidocaine all the time. A lot of doctors don't like that, I guess, because you got 4 sticks instead of 2, but they use the small needles, you know, and if they do it right... The other one people are talking about is this salve you put on an hour early, you know, to kill your nerves....I think that should be pushed more, you know. The staff would say, "Whoa, that's not good", it will harden up your arteries, and stuff like that, but the staff wants something for them, to make it easier for them, quicker. I don't buy that. If they have to stick me, they should make it as comfortable as possible. Fear. That fear is real. Like Julia. Boy, I'll never forget it. She was screaming and yelling. This was in Chicago. She was screaming and yelling and I asked the staff does this happen very often? And they says every time she comes in. Now there somebody should be taking care of her and finding what's going on and they'd see how easy it could be, especially with something like this spray stuff. Or for the team to do it, because maybe she doesn't know that much about wanting to do it. I've got it down real good. Sometimes I never feel it. Not at all. Other times, if they're in a new area, and you don't quite hit the area you sprayed, then it hurts. But generally, it does a good job. They've got to be trained, you know, when to do it. And, gee, David is really good. He zips that old needle in there, he has a snap. He says, "I do it, a lot of times, people say they don't even feel it". But that's just the skill. When you have that snap, you know, you might go right through the other side. I've felt it. It happened to me the first time they used the venous side on my graft. It went right on through and boy, I felt that pop. Sure did hurt. But I mean it's so important to know how to do it and do it properly. And when they pull out the needle, it's important to pull it straight out instead of, well sometimes they pull it sideways. That big black woman, that transient tech from someplace, she was careless, she'd pull it out and I felt it scrape along the inside of my graft. Pissed me off! Could have damaged my arm! My arm is in good shape now, I keep it that way. I don't want it damaged, that's what upset me. You know, and act like they don't care. Anyway, you have to be very careful to pull it straight out. But, then as far as the run is concerned, it's just a matter of being comfortable and trying to keep busy. Or sleep. A lot of people sleep. But then when they're awake they only watch TV. That gets pretty boring. Time goes, you know, it seems like it's a lot longer. But if you've got something to do, it's better. That's why I don't mindAnother thing is the length of the run. A lot of people want to get out of there early, you know, get me on, get me off. Sometimes if you get in late or they get you on late, you know, cause I'm on the last shift, they say "you want to get off at your usual time?" I say no, I want to come off in 4 hours. You know, we're paying for 4 hours, I need 4 hours, then I want 4 hours. So I push that, too. Especially on Friday nights. I want to go into the weekend in as good of shape as I can. Lots of people won't stay for their whole treatment, and that's a shame, cause then they go into the weekend with a short run. And wonder why they don't feel up to par. And another thing I'm concerned about is making sure about the cleanliness of the machines. These are high tech machines, and it's very important they be cared for properly. Then I think that people should explain to the patients when they come in there the technology behind the machines. That never gets done. Maybe they think the patients can't understand it. There's some techs, you know, they just want you to get in, sit down, shut up and let them do their thing. You get that feeling. I think they should explain about how the machine works. I mean, just the basics, you know, the chemistry of it, how the kidney works. I read up on it, but nobody told me exactly how that artificial kidney works. And I think people would feel better about the program if they knew what it does. It's a wonderful machine, you know? They should have a little program, you know, when people come in to start

dialysis, maybe a little class. Before they go on dialysis. I think if they know, they'd feel a lot better about it. Because, what's it really doing? They don't know anything about it. It takes the blood out and puts back and supposed to be better. But by just drawing a little diagram, and talking about what they can contribute to your dialysis and cleaning your blood, and the chemical aspects of it, like your potassium and, um, well, mostly the potassium, but, all of it. And its, um, a matter of getting it integrated into your life. has to be, like going to the bathroom. You've got to go! And the matter of how it does it, what it's doing for you. It's important.

You've never missed a treatment?

Well, no. I've extended my time, because I've been traveling. I've never missed a treatment on purpose. No, I make it a point to get my 3 treatments a week. I may take one on Monday, Wednesday, and Saturday, which works out all right, because I behave myself as far a fluid intake. And people don't understand that very well, either. They're told about it, but they don't really understand the importance of it. Back off, and don't abuse your body. What I've found, too, is sucking ice cubes when you're thirsty. And I also, when I take a glass of water, I rinse my mouth out with it, with the water. I'll do that twice with cool water, and then drink a little bit, don't fill the glass up, maybe fill it half full. A lot of people don't do that. They'll take a full glass of water and drink it, or beer or whatever. Beer is one of the biggest problems with these guys. They take on a lot of liquid. Especially on a weekend. They'll drink up Saturday night, and then again Sunday, and come in with too many kilos on. I try to keep my weight gain below 2 kilos as a maximum. Usually it's 1. Last night, or rather Friday night, I came in with 0.8 kilos and that worked out well. I asked the doctor to increase my dry weight. Pretty much anything I want, they'll do it. Cause I guess they think I know what I'm talking about. I mean, it's my body.

Thank you so much for taking the time to talk with me. I will call you in a couple of days to see if you have anything to add or clarify.

Co-participant # 03010161

I started having kidney problems years ago. I went to Dr. Downer in, probably 19.... hum, probably about 1988. And he told me that probably within about 2 years I would be on hemodialysis. I had 33% use of my kidneys at that time, and within 2-2 1/2 years I was down to 10% and I had to go on hemodialysis. First I went on peritoneal dialysis for a year and a half, but then I had problems with a lot of infections in my stomach, so I can't go on peritoneal no more. So I had to go back on hemo. Hemodialysis ain't the best thing in the world, but it's better than dying. That's what it does. Now the problem I have on it, you get home and probably 3 or 4 hours, your, my body's pretty tired. But most of the time I feel real, real good. Another downfall is if you go away you, sometimes it's a nuisance to get into other kidney dialysis centers. The medication I'm on right now isn't real bad. Only four kinds of pills, which isn't real bad. Control blood pressure, and control my shakes, I shake real bad, and I'm on one aspirin a day for blood thinner. Um, as far as, um, I don't know what else to say, but as far as my personal life, it's changed a lot for the simple reason I can't drink a lot of fluids. That bothers me. I can eat about anything, but you got to watch your intake on your potassium and phosphates. I don't have a sugar problem, so that helps me a lot. As far as, as far as other personal life is, I don't have any problem with the sex part of my life, it hasn't bothered me in that part yet. Not to consider I'm 61 years old.

If you're 61 now, and you started dialysis back in 1988...

No, '88 is when my kidneys started going down. I started in '94, doing hemo. I was still working at that time. When they told me I had to go on kidney dialysis I went back to my company and I asked them if I could still work, you know, I wouldn't be able to work overtime. And they got with the union and they said no, they'd have to retire me. Because you had to hold over, and I couldn't be held over. No, they didn't want me, and, um, so I told them I could have a kidney transplant and they said they really didn't want to take a risk of being liable, so if I got a kidney transplant infection, I could sue them or anything. So I had to retire.

It doesn't sound like they were very supportive.

No, not when it comes down to, not when they found out what I had. Kidney failure. There was another fella working there for a long time, he was on a kidney machine, then he retired, and, ah, I don't know what else to say, but, trying to think of some other stuff...Go ahead, ask me some other stuff.

Remember, I can't prompt you.

Okay. Well, I go to the kidney center 3 times a week. 3 1/2 hours each time. Every other day, Monday, Wednesday, Friday. I drive myself. I've never had any problems yet. Driving. Well, the worst thing is they have to poke needles in you. Big needles. One going one way, the other going the other way. In your arm. That's not a very good, um, situation. And your veins get swelled up big, 'course, mine isn't bad yet. Not yet. What do they call that, a fistula?

Yes.

Well, they put needles in there, and it's made out of plastic, an artery and a vein together. And they put the needles in there. This isn't my first one, I've had 2. The first one, they didn't put the plastic tube in the first one. I just had the vein and artery. It was only from November of '94, um, to, um, November of '95. Oh, excuse me, January, then I went on peritoneal. I only had that one for a little while. Then when I got off peritoneal they went to this one. I had one, whacha-call-it, up here in my neck, I don't know what they called it. Oh, a permcath. I had a permcath in there for 3 months. While the fistula healed in my arm.

Sounds like you've been through a lot of procedures.

Yeah. I've had, when I was on peritoneal I've had infection in my stomach real bad, a staph infection in my stomach real bad, and, um, you have, what do ya call it, hoses, balls, hanging out of my stomach. To pump the infection out. Drains, I had 4 drains. And stomach pumps on me. And I punched a hole in my colon, and I had to have a colostomy for 6 months, then I had to have that one removed. I don't know what else I can really say.

You mentioned that travel was hard for you, to go and have dialysis at other centers?

Yeah. When we go out of town, the social workers at our dialysis center calls the social worker at the center, wherever I'm going, and they pretty much set stuff up. I just take the, um, the last week's run with me. You know what, then I get EPO shots, 3 a week. And that other stuff, the zemplar. How often do I get that, once a week?

It's different for everybody. Some get it once a week, others 3 times a week, some don't get any.

Yeah. Maybe I get it 3 times a week, sometimes they put it in the machine while I'm sleeping. And sometimes in a great, great while, I get that iron, that iron shot. Cause they give it in the machine, too. And I take vitamins. One a day. But, the hardest thing, like I say, about getting on a kidney machine is, in the U.P., they got 3 units, but usually I can only get in one, cause the other ones are all filled up. And it's a big problem with kidney failure, every place you go.

So you're not as mobile as you'd like to be?

No. You can't pick up and go. It makes it rough. My brother has a cabin in the U. P., and I like to try to get up there a couple times a year. We used to go hunting from it, but I haven't been able to do that cause my hips were bad. But maybe this fall. But other than that, I don't know, I guess, maybe I'm not the best one to get a report from. But I feel pretty good, maybe you ought to ask some of 'em that don't feel so good. But I'll do what I can. Yeah, most of the time I feel really, really good.

Now, you mentioned that you have to watch your foods, your diet and fluids really close. Was that a big adjustment for you and your wife?

Not for my wife, so much for me. If I go someplace, I know just about how much fluid intake, and if there's any fluid in the foods I eat, so I have a pretty good, I know, without following the diet straight, what I can take in. It hasn't really changed our life as far as what we cook. Or what we drink. She drinks what she wants and I know what I can and can't drink. Maybe a little in how she cooks. Like she soaks the potatoes to get the potassium out. Drinking is a problem, like if you go to a party. You can have maybe one drink, 2 at the most, and your fearful about that. I don't drink alcoholic beverages, I can but I don't. I drink water and some pop. Mostly water. I don't drink coffee. Not because I can't, just because I don't. My kidneys stopped because of over the years of medication for high blood pressure, so I don't.

So the medication caused your kidneys to fail?

Yeah. Course, if I'd have taken care of myself, like anything else, like I'd say okay, I'm on blood pressure medication, but I'll have me a few drinks, I don't think that helps anything when your on blood pressure medication. They didn't say that was the problem, but they said it was all them years I was on medication, just got the best of my kidneys. It's not a problem in the family, we don't have any kidney problems in the family. So it's not inherited. I'm on the transplant list over to, um, over to Mayo. I think, or whatever it's called over in Minnesota. They put me on the list there, I went over there, I think in '95, they said it would probably be 3-5 years. I called just recently and they said they don't have any idea, but they said that I should be getting close. But I got O positive blood, and that's the type of blood that needs a lot of kidney transplants. If I had a different type of a blood type I'd probably already have one. I'm hard to match cause I'm O positive, and there's so many on the list. So they don't have any idea of how close I am to getting

one. They told me it would be maybe up to 5 years, well, it's gonna be 4, no, it's gonna be 5 years in August. It's a long wait. But then they have to draw blood over at the clinic and send the blood to Mayo clinic once a month for the transplant blood. But as far as, um, I don't know what that's called, when you have, when you gotta have the tissues, you know, when you got to have 6 of them, and 4 match?

Tissue typing?

Yeah, tissue typing. Of 6 of em you get, you gotta match 4. Or the kidney will reject, the body rejects the kidney. Whatever. Especially with the same type of blood. Then you got to be on 3 kinds of anti-rejection medicine. Medication that makes your face swell up. You've probably seen people that have come back and had their faces all swole up, that's what causes it.

That sounds very unpleasant. Yet you still want to do it?

Yeah. For the simple fact that I can go back to leading a normal life. Go places I want to go, do what I want to do. More freedom, that's what it would be, more freedom. That's for me, personally. I don't think it would change anything between me and my wife. She don't have to give me no shots, or nothing like that. She did when I was on peritoneal, she gave me lots of shots. Well, my wife is pretty level-headed. They took her down there and explained to her what it was all about, and what was going to happen, and she just accepted it, you know? It was a freak of life. But it could disrupt, I guess, if she was a tense woman I suppose it would bother her a lot. Yeah, she'd never give a shot before, and the guy was showing her what to do, they wouldn't let me give my own shots, I shake too much. He said I might stab myself when I'm trying to put the stuff in the needle. So he showed my wife, and she'd never given nobody a shot before, and she started giving me shots, and she done it good. I mean, she didn't jab it in or nothing, she just, like she'd been doing it all her life. And she took care of my wound real well, in my stomach, when I had that staph infection. Which was all kidney related. And then they had to put this catheter in my neck. And they put it in my neck, and they told me it would only be for about 2 months. And they put a tube in my left side. Well, when I went in, they didn't do that. They pulled that one out and put this one in. And I just got over peritonitis and I got peritonitis back and that's when I got the staph infection. That was enough. But, ah, as far as, I mean hemodialysis, it's the only way to go, I mean, it's the only thing you can do, you haven't got any choice. It could be a lot worse. But I don't have as many problems as other people. I don't have sugar, and that makes a big difference. If I was gonna complaint, I guess really one of the biggies is I don't believe they train the people that's pokin the needles in ya enough. Sometimes they get em in, you know, right next to the wall, and it kicks the machine on or it hurts a little bit. I think they should be trained better. That's one of my kicks. Then you gotta watch when they pull the needles out that you clot and don't start bleeding. When you get home you gotta make sure to leave your bandages on, oh, I don't know, 8-12 hours. I usually leave them on about 8, then you're supposed to put Band-Aids over them to keep from getting infection. And keep them covered if you're gonna work outside, so you don't get infection in your line. But as far as the center down there, I think they're, the staff is overworked for as many patients as they got. That's the way I feel.

What makes you say that? Why do you think they're overworked?

Well I think the on and off time is where it shows up. You get, they get in a hurry, and sometimes they got too many patients to come off at once, and your time to come off comes up and you run over. Or you need somebody to help you clot, not me so much, but some of the other ones, gotta help them or watch them.

So people aren't getting enough attention?

Right. And personally I think we need at least one more doctor in there, our doctors are so spread out. They've got so many places they've got to travel. I think they could maybe take better care of some of the patients.

How often to you see a doctor?

I see one about twice a week. Usually Friday, you know, they're there if you need them, you know. But that's what I'm talking, you know, my personal thing. The main thing, I think, is they're understaffed. You get good help and pretty soon they move on to someplace else and you got to hire and train all over again. I don't know what the problem is there where they need bigger wages or whatever. I have no idea, but they should do something to keep the good help. But I go to these other clinics, and they, all them ladies or men or whatever, they stay there for a long time. Not a big turnover. I asked them up there, the one in Marquette, that's for Michigan, northern Michigan, Wisconsin, Minnesota. They said when they changed over to GAMBRO they had a problem, too. But they don't have a big changeover in help. Course they don't have the number of patients. They only got 28 or 30 patients a day, where we got that many every shift for 3 shifts! That makes a lot of difference.

I think what I'm hearing you say is that you wish there were more individual attention.

I do, I do. What I would like to see, say, you're an RN, maybe you could take care of one side but I think the tech 1's and tech 2's should have their 4-5 people and take care of those people and not take care of somebody else, that would help. I mean, if you've got 4 people or 5 people or whatever you have, keep them 4 people and take care of them and let somebody else take care of the other 4. If you're short, then you gotta help. I think that's one of the problems. I think another problem, we need some of those modern type chairs, some of those chairs are kind of old. I've seen the chairs that, when you set in them, it automatically weighs you. And it shows your weight going right off. And it's comfortable. Nice comfortable chairs.

Yes, you do sit in those chairs for a long time.

Yeah, it is a long time. I do a little reading and crosswords, mostly. I try to sleep. Sometimes I'm not that tired, but I force myself to sleep so time goes faster. Otherwise it is pretty slow. It's funny how just sitting there leaves you so tired out, cause even if I sleep there, I still go home and feel tired. The longer you're on, it seems like, the more that happens. The first couple years I was on, I didn't really notice it. But now that I've been on hemo this long, it does bother me more than it did. The tiredness. I get pretty exhausted when I get home. Sometimes I sleep, sometimes I just sit in the chair and watch TV. I have to get off my legs, cause my legs get real tired. Mostly it's just my legs. But if your legs are tired, you're tired all over. (pause to answer phone) That was my son. I have 3 kids. My one daughter's married, and one of my sons still lives with us. We thought about getting a transplant from one of the kids for a while. My daughter can't give because she, uh, that liver problem, what's it called? Hepatitis. My other daughter started to take some of the tests and, I guess that guy she's married to now didn't want her to get all scarred up or something. And my son, I don't want to take one from him right now, he's too young. If I really needed one right now I'd probably ask him, but I don't know if we're compatible. I think he's got O+ blood, I don't know for sure. He might be compatible. But I haven't asked him yet. He's 22 years old, I figure that's a little bit young. They said there's a possibility of him having kidney problems, very unlikely, cause it isn't inherited in the family, and there isn't any problem on my wife's side of the family. In fact, I was talking to Mr. Maycroft, you know, from the Square Tappers?

Yes, I know him and his wife.

Okay, he said he give his brother one years and years ago and his brother's doing well and he's doing well. He said he never even knew it, other than when they first took it out. Said it wasn't bad t'all. My daughters don't have kidney problems, and my son don't have kidney problems, which I'm very happy for. My aunts and uncles all lived to ripe old ages. On my mother's side. On my dad's side, they died real young. Heart problems. The rest of them, they're all old. I think my youngest aunt is, um, 72 years old. And I think the oldest one is 91. Me, I don't really have too many other health problems except this kidney thing. I had 2 hip replacements. The second one was just last August. I went up to the U.P., and got on the kidney machine and it went out of joint on me and I had to stay in the hospital all night, then they put it back in, put me to sleep. They couldn't get it back in. That was like a muscle spasm, like a cramp when you get off the

machine. It pulled the joint right apart. I had to do it before, but it was the first time it pulled apart that far. Boy, up there to get somebody in to do that, all the guys, they were out hunting. It was September. One guy, he was supposed to go hunting, but he had to keep me there, give me X-rays. And they called one guy from the woods, he had a radio with him, he come and give me the anesthesia. And the doctor who was on call, he was a baby doctor, so he didn't know anything about what was going on. So they had to call in a doctor from another hospital. He was in Iron River and it took him about a half an hour to get there. He's the one who put it back in place. They said if they couldn't get him in, they'd of had to send me to Marquette and they'd of had to operate on me. Anyway, they had to put me to sleep, to relax me, cause they said when I was awake they couldn't put it back in place. But I've never had any trouble with it since, just that one time. No, I don't have any other, um, ailments. Thank goodness. Except for that food poisoning I had a few weeks ago.

I think that's the only time I can remember you stopping your dialysis treatment early. You sure were miserable.

I've never missed a treatment. Never been tempted to skip. Never even thought about skipping one. I figured that's what would do me good. I have went an extra day, like when I went on Thursday, and I went to the U.P. and wouldn't get on the machine until the following Monday. But that extra day, it didn't bother me. I just watched my food and my fluids. You know, another thing that dialysis takes, takes potassium out and your phosphorus gets high. I had that once and I broke out in, like hives. Itchy. And just my lower body. I got really itchy, red. Never had that until they put me on hemodialysis. That's when I got bad, and they put me on there. And I got real sick. I was gonna go on at, on a Monday, and, um, this was on a Friday. I got home and got into bed. I thought I was a goner. So I went right down there and they put me on the machine at Mercy hospital. They put me on for 4 hours, and oh, within I'd say an hour and a half I could feel the difference already. I could feel at least 50% better that quick. Just with that one treatment, not even all the way through, made me feel that much better. I mean I felt terrible, terrible. Just sleep, wanted to sleep all the time. Didn't care, I could be sitting in a chair and by the time I got to the davenport, I could take another nap. Do anything outside, walk around, and I'd be tired. I was trying to work, walk up and down stairs, and I could hardly do it. But that was really good, when they put me on for that reason. I have a little phosphate problem, and that gives you a little bit of a bad taste in your mouth. Well, potassium will do it, too. You get a bad taste in your mouth if it gets too high. But I mean you get itchy. I can tell when my potassium gets high, I get real itchy.

I didn't know that potassium would do that, too. Now, you talked about cramps. Do you get cramps on dialysis?

I don't get dizzy, but I do get cramps. I get quite a bit towards the end of the run. But that's a lot of the time cause I put a little bit too much fluid on. Maybe a couple times a month, it does bother me at home, I get leg cramps at home. But not too bad, when I stand up they go away. Sometimes they're bad, like in my legs and in my toes. My toes will go, all like, that there, you know? Stand up and get that cramp out of there. The cramps ain't the worst thing you could probably get. If you watch your fluid, you usually don't, but sometimes you get 'em anyway. Sometimes you get sick to your stomach on it, if you have too much fluid on and they take it off'n you. Pretty sick to your stomach. Nauseated. But other than that, no, I don't have a whole lot of problems. They gave me a list, when you first go on hemodialysis, they give me a list, and you just follow that list and you pretty much learn, you know, you can't have beans and other things you can't have, and stuff like that. I do cheat a little bit on mine, but if you just take a little bit, it's not gonna bother you. But like tomato juice is bad. Potassium. But once in a while, I'll drink one of those little cans. Now I don't have a problem. But I've talked to other people, and they have a whole can of tomato juice and it gives them an awful problem. But not me. Another juice you can't have is orange juice, cause that's got a lot of potassium, but sometimes I'll drink a little bid of a small glass. Dr. Downer told me that if I wanted to eat oranges, the best time to do it is to bring them while I'm on the machine and eat them when I first get on. That way the machine will take care of the potassium. But foods, most of the foods you can have. Except what's on the list, beans, and, um, and stuff like that, you gotta watch it. Got a lot of

potassium in potatoes, so you gotta soak them before you cook them, boil them, or whatever you want to do. I don't really have a problem with eating any kind of fat meat or anything like that. I get enough protein, eggs and cheese, I really don't have a problem so far. Sugar, cause I don't have any problem with that, I don't have sugar. That'd be tough, the dialysis restrictions plus the sugar restrictions. Thank god. (pause to speak to wife) I guess if I was to give advice, like to a new person, well, the first thing I would probably tell them is about, ah, when you first go on, they'll put a catheter in your neck. And then they'll put one in your arm, that'll have to be in there about 6-8 weeks, and they'll use the one in your neck. Sometimes you have a problem with the one in your neck because it does get infection pretty easy. And what they do, they take fluids out of your body, and what they let your body do, like salts, potassium, phosphorus, but anything else, you know, you gotta let em know. You gotta stick to the diet, and follow the doctor's orders as best you can. When you get used to your own, then you pretty much know, you know, what to do. But I really would, I would like to talk to some of the other people. They don't listen real well, I know that. There's a lot of people like that. And if you're doing everything you want to, then all of a sudden, you can't. I mean, that's a big shock. Liable to be a big shock to the family, but more shock to you.

How was it for your family?

My family just pretty much accepted it. Accept it real well. I wouldn't say it was scary. Because they told me it was coming. Like I say, they probably told me 2 years ahead of time, that I was gonna lose my kidney function, it just kept getting worse and worse. So when 2 years got there, I guess I was kinda immune to it by then.

You and your family had already dealt with it?

Yeah, yeah. We'd already dealt with it. They had already took us through the unit and showed us what they do. Talked to me about it. I don't believe they showed me enough, though. They took me through and explained, but I think you should go through more than once. Fact is, what I think they should do before you go on there is have you come in and visit, see maybe an on and an off. And teach you in between. Say, you can go back to this individual in a little while, see how they're doing. This could happen to you, you know, cramps, sick to your stomach, you know, if you're overweight. And at the end, make sure you clot good, hold your fingers over it. But I really believe that would help. Just in case they want to do it, I really believe that is one thing that could help them. I think you should stay in here longer than just a visit. Because when I walked through there, I walked through there, or somebody showed me through, and you got a hundred other things on your mind, you know, when they say you got to go on a machine. The people sitting there, they don't look that bad, you know, but if you go and stay with one of the patients for a while, from the time they got on the machine, I think they'd learn a lot more. And talk with the patients, if they get one that likes to talk. Some of them don't like to talk, you know, but like me, I'd talk, I'd tell 'em what it's about. How I feel at a certain time, and, um, like how you can tell when your blood pressure goes down. Like when mine goes down, I can feel it in my face. I get, I don't know, I get kinda weak in the face, I can tell when my blood pressure's dropping. Right around my mouth. That's the first place. I don't know why it wouldn't be all right for new people to just come in and sit and watch, either. Wouldn't be no more work. But I think that would help a lot, I really do. You know, when the new company took over, they said this and this and this would happen, and I haven't seen any of this happen yet. I haven't seen that big a change from when Mercy was running it to with the company we've got now. My bills haven't changed, either.

How does that work? Do you get the bills directly, or does it go through the Medicare/Medicaid system or to your insurance?

It goes right to them first, and then they send us a, um, whachacallit, um, a printout. Of what the treatment is and the other stuff, too, like the EPO shots, iron, and machine time and all that. I don't even know how often we get them. In fact, I just got some the other day.

And it itemizes it all, breaks the charges down?

Yeah. And it tells how many times you're on and how many minutes and all that. That's how, well, George, you know, he gets the same thing. And he looks to see how much everything costs. I can't remember right now how much it costs for a treatment, but it's plenty. It's plenty. I don't have to pay for anything out of my own pocket. I got PHP, and what Medicaid don't get, PHP picks up. They been real good on that, but they're real lax on some of their pills. They change a lot, where it hasn't affected me. But they wanted to put me on that one arthritis pill, and they wouldn't pay for it. And I talked to Dr. Downer about that and he told me to just take stuff across the the counter to do it. But he told me, what was that stuff he recommended?

Celebrex?

Yeah, Celebrex. And he said that they found out that people's dying from tumors in their stomachs, so he was kinda shying away from that after he checked that out. Not very many, but he said we don't want it to happen, so Dr. Downer just told me to take some kinda, not aspirin, but anything else. Over the counter. They told me Motrin was a no-no. On kidney dialysis, that's a no-no. It gives you stomach ulcers, or something. So I said all right. When I was over in the hospital with my hips, they give me everything imaginable, but I still hurt. It didn't help. It didn't help me. Only thing that helped me was when they took the damn thing out and put a new one in.

Was there any problem for you with that surgery, being a dialysis patient?

No, none whatsoever. Any operation I had, kidney dialysis didn't have nothin to do with it. No. Fact is, Dr. Petty told me for being on dialysis, that I heal fast. That's another downfall of dialysis, your wounds don't heal up as fast. Even without sugar. Because it takes so much stuff out of your system. Knock on wood, I was really fortunate she told me I heal super, super fast for being on dialysis. Fact is, when they done my stomach, I healed too fast, she told me I heal too fast. She told me I should heal slower than that. Well, cause they wanted it to heal from the inside out and I was healing from the outside in. That wound was probably 6 inches long, inch and a half wide, probably. I mean I was laid wide open. I had visiting nurses come out. Dr. Petty said when she first opened up, when she first opened me up she took out 3 handfuls of infection. That's how bad I had it in there. That was tough.

You've been through a lot in the last few years.

96, it started in 96. In 96, I was in the hospital, it went from being 2 days to being 2 months. I went in there for peritonitis, and I stayed 27 days. For my hips, I only stayed 4 days. The right hip, I had to have physical therapy on it, or whatever you call it. And then on the left one I didn't even do any. I just walked. They didn't recommend any and I didn't ask them about it, so I just went and did it on my own. Feels good. There anything else you want to ask me?

Not unless you can think of anything.

No, can't think of too much right at the moment.

Well, I'll be in contact with you in a day or two, so if you think of anything you want to add, please let me know.

I'll do that.

Co-participant # 04020136

Okay, just to reiterate, the whole idea is for you to tell me what is significant for you, as a dialysis patient.

I don't know, I just take one day at a time, I don't think about the next day. But I know I have to stay low on my kilos, you know, they tell you it's harder on your heart to pull off more kilos, the more you have on, you know. So I try to keep that down. I do like hemo better than I do PD, but I don't think you live as long on hemo as you do on PD. That's what I was told, that PD patients, they live quite a while, cause they do exchanges every 5 hours like I was, and then go on the machine at night. This way, you gain for 2 or 3 days, and you go in there, and they're gonna pull it off in 3 hours. Yeah, the hemo is harder on you. But I like it better. That's why nobody's asked me about PD, about coming back. I feel better. I had some problems on PD, I have a lot of adhesions in my stomach. And like the nurses are asking me if they're gonna put one of those things in my arm, but I form blood clots very easy. That's why the minute they take this heparin out of here in my permcath, they've got just 10 minutes to get my protime and get my heparin back on. So it doesn't clot. But yeah, I like it better.

Why is that? What makes you like it better?

Freedom. Except you can't have what you want to drink, and can't eat what you normally would. But I can find something my day off, you know, and go do something. I know they say PD is better for you, but I'm kind of scared, I've had a lot of surgery, I'm kind scared to go in there and them tell me that they can't do one. So I don't know. Maybe eventually I will try for one. And they did put me back on the transplant list. Downer did. Tokiwa took me off, but he put me back on. She was a little bit upset about that, I think. She just came up and asked me what was up, and I told her. And she just walked away. I'm young, I'll be 36 this month, and why shouldn't I be on the list? They said I was actually on the list, I just wasn't active, so now I'm fairly high on the list.

Why did the doctor take you off the list?

Well, I thought maybe it was because I had that shunt put in my right leg. So they can't put a kidney there, only on the left side. I thought maybe it was that, or because I form so many blood clots. I've had blood clots in my left groin, and my lung. On the right side I had one behind the knee and the thigh. So maybe she figures, well, I did have a transplant before, and it worked like 4 days. And when they took it out, it was all clotted off. So I don't know if that's what she's thinking of, or what. But Downer talked to Bouman, and he said that he'd have to get me the exact kidney that would work. The other one was way too big. And that was a cadaver, so they don't know if it was wrecked. (long pause) Sorry, I'm really drawing a blank. Can you ask me a question or something to get me started?

How about if you started with some background, how you came to be on dialysis?

I graduated in '82, and I worked for 2 years when I got the butterfly, and my skin was turning purple. I just hurt all over. And right after that they found out that I had lupus. And I was in the hospital a lot with lupus. My kidneys failed in, I think it was '93. I think it was '93 they failed, and the lupus just, well, went down. I've only been in the hospital because of the kidneys since then. That's what did it, the lupus.

And you haven't had any more lupus flareups since then?

Nope. And Dr. Hylland said my sed rate is at zero right now, that's excellent. See, I go to him every 2 months. I gotta go to the eye doctor and get my eyes checked cause I have to take Plaquinil for the lupus, and the Plaquinil can wreck my eyes. I have to make that appointment yet.

Sounds like you have to deal with a lot of doctors.

Yeah. But the bad thing is at the kidney center, you got 4 doctors, and each one tells you something else. So I try to stay with Downer. He's the one that seems to be on my side. And other than that, I don't know, I just enjoy the days I'm here, you know, spend time with my dog, go places with my mom, my sister. I don't just sit here. I used to. When I came down with lupus in '84, all my friends just went away. I don't have any friends now. They went away like it was contagious, so I just hang out with my family. And my nephew, he's 16. He just started driving. So, I don't think about it.

That had to be really hard.

It was. Cause I had a lot of friends. I graduated from Whitehall in '82. It doesn't bother me, it's their problem, not mine. Like last night, it was my mom's birthday. And about 6 o'clock she says lets go to bingo. We were late when we got there. But we get out a lot. She takes me places, she won't let me just sit here. She's got friends, and her friends are my friends. I get along better with older people. It doesn't bother me. I've been friends a long time with my sister. She's only been here, not quite a month. I'm never bored. And I like to knit. You've seen me making that one for my sister. Mauve and beige. Now she wants a dark green one. She changed the color of her bedroom, but she got a blanket rack and just put that one on the rack. In her living room, it looks pretty. So now she wants a green one. It'll take me a while, but that's okay. It keeps me busy. Never bored. Sometimes I'll take off and go to Grand Rapids and see my brother, or just drive down to the lake. Sometimes I wonder what it would be like if my kidneys just miraculously started working again. I don't know. I'd have more fun, I guess. Probably get a job. Have a normal life.

What's not normal? I guess that's what I'm getting at.

I don't go out with people. Dancing or out drinking. Or if I go to a movie, it's usually with one of my sisters. But that's not very often. I'm a home person. There's sometimes I don't want to go to hemo, but I go, I don't miss any of my appointments. But if I got a kidney, like I say, get a job, maybe have a husband. I don't know. You know, I went with this one guy and he asked me to marry him 3 times. I said no. He said I'll take care of you. I said I don't want no one taking care of me. I take care of myself. So now we're just friends.

So do you think that the kidney failure is keeping you from having relationships?

Oh, yeah. Cause I don't go out and meet anybody.

How come?

Cause I don't want somebody to bump me. Start bleeding or something. I don't know. I just worry about it.

You feel fragile?

Yeah, that's a good way to put it. But I go places with my mom. I don't know. I just don't really think that much. I get depressed, you know? It's like everybody says, you know, you could get killed just walking out the door, but it don't help, you know? I think the biggest thing would be, you know, a job. Get out more. And I'm scared to do that now. And I'm kinda scared of people, too, you know? Some people can be cruel. I feel safe right here. Probably not very wise, but ...I don't know, I like it here. Sometimes I sit and think, instead of getting lupus, I coulda got, coulda kept my job that I had in '82, coulda found somebody and got married, had kids. I had a hysterectomy in '91, I had endometriosis really bad. But sometimes I think, like I tell my mom, what if I'da had kids when I was 18? She said "I'da killed you". And I says, but you woulda had a grandchild. That would probably be 18 by now. Things might have been different then. With a child. I don't think about it too much, cause like I said, I get upset sometimes. So if I feel myself brooding, I quick turn on the TV. Or go take my dog for a walk in the backyard. We stay in

the yard, cause he's goofy. If he sees big dogs, he thinks he's bigger than them. And I don't want one to jump on me, see? So, I don't know. I don't go bowling, I just don't do much. But I'm not bored. You probably would be bored if you didn't work.

Maybe I would. Sometimes I think I would, and sometimes, I don't know.

Clean your house, not worry about people coming in your house. My mom's retired, so we go do things. She found her boyfriend, they were boyfriend-girlfriend when they were 15, and they just found each other after, let's see, they were 15..... 49, no, yes, 49 years. And he just retired. Gonna get married. They don't know if it will be this year or if it's gonna be next year. They go fishing, they always ask me to go, but I still think they want to be together, so I just let them go by themselves. My sister wants me to go fishing with them, so I gotta get me a fishing license so I can go. But I always carry my beeper with me, I just slip it in my purse so I don't forget it. I never forget it, I can't walk out the door without it. It's for my transplant. Nobody else has the number, just St. Mary's. And nobody else can have the number, otherwise I have to pay for it. Somebody does this for the patients, so they can have the pager for free. All I have to do is change the batteries. So, I don't know. I'm probably not giving you much to go on.

Oh, you are. You really are.

On PD I had a lot of freedom. But you always had to be back here, like at noon for an exchange, or at 5 o'clock for an exchange. Cause every time I got pseudomonas I was at somebody's house doing an exchange. So towards the end I got to the point where I'd only do it here, and nowhere else. And if I go someplace with my mom, well, my mom don't run by a clock. So you have to do it at other people's houses, and it just, what it seemed to me, was, it was always at someone else's house. I don't know if it was dirty, or if they had a window open and I didn't know it, or what. Now here at the house, the back bedroom was just for exchanges. There's a twin bed in there, but everything else in there is mine. And now that I'm not on it since November, she slowly put more stuff in there.

So you've been on hemo since November? Of '98?

I was on hemo off and on since I started dialysis. In '86. Four different times I think, I was on hemo. But this time, it's been since November. I just, I don't know. Like I said, I just think about today, I don't think about the next day. But I do watch my fluids and stuff. I don't know, it's different. I don't wish it on my worst enemy. I don't think anybody would. But I have a hard time sitting there those 3 hours. I hope I don't have to go to 4. This left leg, I've been taking Percocet for 2 years for, and Downer says there's nothing they can do. And when I sit there so long, then it starts to ache, and I start to squirm. And sometimes I leave my feet down so I can put pressure on it so it doesn't hurt. But when I go to bed, it's terrible.

What is it that makes it hurt?

Neph...rolpathy? Nephropathy. That's it. It's just, when I'm on it, I'm all right. But when I'm off it, or even sit like this, sometimes it starts. Especially at night. So what I should do is take a pain pill at 8 o'clock at night, but I don't. I take it when it's too late. Then I sit there like a half hour in pain.

Is that from the lupus, or are you diabetic?

Not the lupus. I don't know what made it that way. I don't know if this makes sense...everybody says....anyway, the first time I sat in that hemo chair, the lower part of my back, it like snapped. And it was painful. So I don't know if that had anything to do with it. Cause right after that, that's when I started having problems with that leg. I told Downer that, but he kinda looked like...he didn't know. Anyway, it happened after I started hemo, cause when I was on PD it didn't bother me. I don't know, it acts up every time I'm in there for hemo. For 2 years. That's why when the nurses call me to come in early, always ask

is it in a bed or in a chair? Cause in a bed, I can't sit up and put pressure on it. You have to lay there. You can only squirm so much. They've put me in a bed twice. And it was bad both times. Even if I sat up on the side of the bed, and they don't want you to do that. Now being in a chair, I can put pressure on it. On the footpiece. Cause I can't reach the floor. That's why even in the hospital, Downer has them get me a recliner. So he knows. Seems like he's the only one that knows. The other ones, they always ask, Lori, why are you still on Percocet? You should be off it by now. So I tell Downer, and he says when you want Percocet, you ask me. I'll get you a prescription. So that's what I do, I just leave Kram and Twu alone. I don't even ask for refills more than once a month. I try to take only one a day, but I have to take one before I go to hemo. Sometimes within an hour or so they say I can take a second one. In the hospital, they always ask me, how many do you want, one or two? If you took two, you'd get more addicted to them, wouldn't you think? My average is one to two a day and that's it. They don't make me feel high or nothin. They just stop that pain. Like my ma says, if she took one, it'd probably make her pass out. But I'm used to all this medication. I'm even thin on top, thin in my hair, and they say that's from all the medication. There's no hair up there, that's it. I don't like that. Next week, I'm supposed to go get a perm, and that makes it look fuller. And I don't wear it too long. So, I guess I'm probably not giving you a lot to go on.

Oh yes, you are. It's obviously had a great deal of effect on your life. And what I think I'm hearing you say is you're probably not married because of it, you're not pursuing relationships because of it....

I don't want nobody feeling sorry for me, or nobody to take care of me. My mom does; she takes care of me, and I take care of her. But that's it. Cause I've been in the hospital quite a few times, had congestive heart failure in January or February, it was almost when Suzanne left, and she almost spent the night there with me. She was there till almost midnight, till they started hemo. I think I lost like 17 pounds, that's what, 8 kilos? That's how much she was pulling off me. Then they had to run me the next day again!

That's a lot for someone your size.

Yeah, I didn't know it, though. So now I try to eat, even if I'm not hungry. Like my sister said, she had a hiatal hernia, and she eats something every 2 hours. Not a lot, but just something. She told me to try that. Half the time I'm not hungry. And I don't eat a lot at one sitting. So sometimes I have peaches, or fresh strawberries, or blueberries, them are next. Then I was eating steak for protein, but they told me it was high in phosphorus, and my phosphorus is high. Like I said, you can't win for losing. They want you to eat 70 of protein, 70 grams of protein a day. There's no way. No way. Especially when you've gotta watch your salt.

Sounds like a challenge. So, you have to watch phosphorus, potassium, sodium, fluids...

Yup. But what hurts me more is my jello. I can't have my jello. Or water. Or potatoes. Green beans. Bananas. That's what I miss. Like I said, I spend a lot of time with my family. It really affected my mom when they told us I'd have to go on dialysis. Every time I go in the hospital, they all come up there and they all think the worst. I had 4 dogs at the time, a St. Bernard who was sick, and a Shitz-su, her name was Suzy, she had cancer, and two other Shitz-sus. The day before I went in to the hospital for starting dialysis, my mom had to have the 2 dogs put to sleep. So that kind of upset me for the whole thing. Putting my 2 dogs to sleep. She said I can't take care of you and them dogs. So that's about 8 years ago, about 7 years ago I got this dog. He's the baby, everybody loves him. But a stranger, he don't like them. Or black people. He lets you know if he hears something. He's a good watchdog. If someone's in the yard..... He knows someone's here, cause that's when he goes in the bedroom. So you gotta do this for a class, huh? Final exam, or something?

For my thesis for my master's degree. What I'm doing is interviewing a few people who are on hemodialysis about their own experiences and perceptions of what it's like to be a dialysis patient.

How many have you talked to so far?

You're the last one.

Last one? I bet they had better stories than me. It's hard. Especially if you want to have a transplant. You gotta know all your medications, and take them, make sure you don't miss them. Some people get sick off 'em. And you gain a lot of weight from the steroids. That's what I was told. Cause they give you Predisone. When I was there before, I kept trying to learn the medications, but I couldn't get it down pat. They want you to memorize everything. Then they wanted you to eat a jar of dill pickles. I like dill pickles, but I told them I didn't like them.

Why did they want you to eat a jar of dill pickles?

For the sodium. To get your new kidney going, or something. They brought me a whole jar, but I said I didn't like them. I wouldn't have liked them when I was done with them! I worry about that, too. Having a transplant and having to go back to St. Mary's. When I had the first one, I was there over a month because he was trying to get it to work. Then finally I got this really bad back pain and he called all the surgeons in and they had to take the kidney out. So then I went home a couple days later, and I had to go back in, I had abscesses. A big old abscess where that was, and they just stuck a needle in where the scar was and it just drained and drained. And then I got peritonitis from that, cause when I did my dialysis, it just drained. And my mom helped me. I'd stand there, and it would just pour out all over the floor, and she'd put a towel down on the floor, and cover the drain, but I still got peritonitis. And then when I went home, they put an IV through here, and when they took the tape off, I got this permanent mark here, from the tape. It's all from the tape. And when the sun gets on there, it burns easy and then it itches. And my sores don't heal either, I don't know if that has something to do with my medications or not.

And you're going to do it all again.

It's scary. Cause the first time I had a bad time. And I'll be in Grand Rapids. All my family is here. My mom can't run down there every day. And I sit here and think, I was bored when I was in the hospital. There's nothing to do. Either stay in your room or put a mask on and walk the halls. I think I started walking too soon, and that's why I got the abscess. I still had pain, you know, it was probably like one, one or two days after surgery I was out to walk the halls. Cause I was bored. And when people come to see you, they gotta wear a mask, and it's hard to breathe. And like I said, I had a bad experience the first time. I'm kinda leery, but I'm on the list. That's probably it. That my family wouldn't be near me. Other than that, it's not that bad. Just, sometimes I lay there and think, should I go back on PD, then I think about the surgery. I don't know. So as I say, things right now aren't too bad. But I don't want to wait until it's really bad and it's too late to do anything about it. But right now my blood work's fine. As long as that's holding me up. I think if they ever told me I had to go on more hours I'd seriously think about going back on PD. There's no way I could sit in that chair more than 3 hours. Anything else?

Well, you did mention that you didn't like to think about some things because they made you depressed. I don't want to bring things up that are hard for you, but I guess that's kind of what I'm looking for. What makes you...

Depressed?

What makes you so depressed about the hemo that you're willing to go through all that for a transplant?

So I can go out and be normal. Go to Parties in the Park, go to the lake. Now I won't wear a bathing suit in public. I won't. I don't know, hang around with my old friends, but some of them are married, and you know married women don't hang out with single women. There's no way I'd do it just to get married. Not

just so I could get married. I'm fine just where I'm at. And there's a lot of days that I worry about my mom passing away, cause she's getting old. She turned 64 yesterday. And she gets tired. I think that's the worst thing that's on my mind. What am I gonna do? That's my best friend. Like my mom says, you're not supposed to think about stuff like that, but you know, she's up there in age. And she does have a brain tumor.

She does?

Oh, she's had it for about 4 years. It's a slow growth one. And they say when it got to 3 centimeters they would do surgery. Right now it's at 2. They said that stress makes it grow. I think they could do surgery now, you know, while my mom's at a good age and healthy, she's fit. Not wait until she's in her 70's and maybe in and out of the hospital. And she's getting married. They just found each other again in November. So that's probably one of the reasons why she's holding off on the surgery. You know, we're like any other family, you know, they all don't get along. They all don't come home. But I figured, if I get a kidney, things will be different. My lifestyle will be different. I'll be gone all the time doing something else. But I always make sure to be here when I'm supposed to be here. If I'm not at hemo, I'm here. I think what helps at dialysis is the nurses; they come and talk to you. They treat you like you're friends. Like Dave, when I walk in the door, he always says "hey LB". I mean, I feel like they're my friends. Some nurses are kinda, they, um, I think they hold back so they don't get close to us. Cause then when one passes away, it's hard on you guys, isn't it? But that helps a lot. Sometimes the TV. When I first started, I wouldn't watch TV a lot. But it kinda makes the time go by faster. Sometimes I do crosswords, sometimes I listen to the radio. And like I said, they come up and talk to you. We talk about their kids, what we did over the weekend. I guess them are my friends, the nurses. When I first went on hemo, they gave me quinine. I take one every day. I usually don't cramp cause I don't have that much fluid on, but like even on Monday when I had 3.1 kilos. It was hot last weekend, I couldn't help it. I didn't cramp. Just my blood pressure goes down. And they got me on plus 6. I cannot go out of there under my dry weight.

Plus 6?

You know, the sodium they set the machine to give you for cramps and blood pressure. If I go out under my dry weight, my blood pressure will be too low. Usually my blood pressure doesn't go up. Like today, I went out at 47.5, right on my dry weight, and I didn't have any problems. But if I gain a lot of fluid, sometimes I feel lousy after dialysis. When I come home, I'm just whipped. And my mom can always tell. I go to bed early. Or I lay in my bed and watch TV. But like today, I only had like 1.9 on. And I feel great. I stopped and got a hamburger on the way home, and I ate it and had some juice. I didn't drink it all, though. But I feel fine. But like I said, if I got more than 3 kilos on, I'll come home just whipped. A couple times my mom had to come and get me because of it. But that's just once in a while. Like one day, I was almost a half hour late because of it. And if I feel really bad, I won't drive. Otherwise, I feel pretty good when I leave there. So that's why I try to stay under 2 kilos. Once in a while I screw up, like the other day, I ate watermelon. And I cheated, I didn't count it as a liquid. My limit is 6 cups a day. You figure you got a cup of milk in the morning with your cereal or whatever, and a cup of water just to take your pills. So I chew gum. Gum or hard candy. And I make that rock candy, and I got root beer barrels, I got jolly ranchers, and watermelon...the hard candy. I eat a lot of hard candy. And I'm doing good at the dentist. I got no cavities for the last 2 years, knock on wood. I go every 6 months. And the last 6 times I've gone, no cavities. When I was younger, I drank Mountain Dew. And when I went to the dentist, I had 10 cavities. I never drank Mountain Dew again. I don't drink a lot of pop. I just drink juices. And water, I love water. When I'm thirsty, I drink ice water. I don't know, I don't know what else to say. Like I said, I don't really think about it that much. I just live day by day.

Where do you see yourself in, say, 5 or 10 years?

I don't know. I don't think I'll be alive. Not that far away. So, but like my mom said the other day, she didn't think she'd live to see 64. You don't know. There's a lot of crap going on in this world, you don't

know nothing. Drive-by shootings, and someone could shoot you when you go in to pay for your gas. You just don't know. So I don't look that far ahead. I just know I'm here now. Last year went fast! The years go too fast. I feel like I'm just getting out of school. I wonder if it's cause I'm on hemo and I go 3 days a week. It seems like it goes so fast. You have a day off, and the next day you're back in there. And the weekend, then it's Monday and you go back in. I went to Six Flags with my sister, the first part of June. For 3 days. A lot of fun. I didn't ride any of the rides. I paid the \$36 to get in, and I didn't ride any of the rides. My stomach won't handle it. And I went there because it was with my sister. I don't go anywhere with other people, just my family. But I don't go to Michigan Adventure or nothin like that. I don't go swimming. I take showers, but I won't go swimming.

Because of the Permcath? The central line you have for dialysis?

Yeah.

So you were gone for 3 days. Did you have to have dialysis somewhere else?

No. I dialyzed Friday morning, and we left. And I was back Monday. We got back Sunday night. So maybe it was closer to 2 days. We went to Florida about 4 years ago. When I was on PD, and I did my exchanges in the hotel room. I didn't get pseudomonas or nothin. Sometimes I did it in the van. We'd turn the air off, and I'd be sweating and all. We went down there for a week. I just did it in the van going down, and when we got there, they would call me at night so they could unlock the door for me so I could use their microwave. Then run back upstairs and do my exchange in the bathroom. People, they understand when you tell them what you need it for. But I wouldn't go into a restaurant and tell them I wanted to zap a bag. But if I want to go to places like that, I can go. But I usually don't like going too far from the house. I feel safe here, I guess.

It sounds like there's a lot of fear involved.

Yeah. I try not to think about that, either. Yeah, like I said, it's mostly one day at a time. I know I've got tomorrow off, my dog goes for a haircut. But, I don't know. It's weird. I don't know. I was 20 when I had lupus. That was in '84. And dialysis was in '92. The thing with the transplant was in '94 or '95. Yeah, that's one thing I worry about. Thirty days there, and went home with an IV. I was out of the hospital one day, and had to go back into emergency because I had that abscess in my stomach. And it's funny because when they took that kidney out, they found an abscess there and they took that out. Well, they took some out and the rest dried up. Then they had to go back in and put a shunt in. And fix the aneurysm. But that one broke, it got infected, so in March they had to go back in and put a different one in.

The shunt is to keep blood clots from getting through?

No. The shunt is to keep blood going down to my foot. There was no blood going down to my right foot, so they used that. He said there was no way to know if it would last until the next day, the next year, the rest of my life. He said he couldn't guarantee that. But I think it's a bigger one than the first one. But they're still finding blood clots. So I worry about that, too. It all goes with the blood work. At first they thought it could have been the lupus, but Dr. Alexander said it's not. It's just my own body, I guess. That's why when I get bumped or something, I always worry. I get bruised so easy. My liver was involved when I first got lupus. It was only working 10-20%. But like the doctors said, it rebuilt itself. So I'd come home from work about 4 or 4:30, and I'd go to bed and get up the next morning about 6 and be back into work at 7. If I hadn't of done that, and gone out running around with my friends, I wouldn't have been here. But I did. When I got out of work, I'd come home and go to bed. I lost a lot of weight then, too, because I was too tired, I just wanted to sleep. And I baby-sat from the time I was 14, up until I was 30. Then I said that's enough. And the 2 kids I watched, he was 2 and she was just born, now he's in his third year in college. I about raised them. Their mom and dad would go to, like, Hawaii, or whatever, for like 10 or 14 days or whatever. I stayed right there. They had horses, and a dog, and a potbellied pig. They had a pond in the

back yard. I feel like I raised them. I feel like they were mine. I found out he smoked, when he was 15, I found out he smoked. His sister said he was going out in the barn and smoking. And I said as long as I'm here, you are not smoking in the barn and you are not smoking in the house. You go out on that deck and you smoke. And he thought that was cool, because he didn't have to hide it. I didn't want the barn burning down. I don't know if his mom and dad know it yet. That I let him do that, but you think of those horses and that barn burning down out there...He'd take a glass of water and use that to put out his cigarettes, and then bring it in and flush it down the toilet. I had no problem with that. Maybe that was wrong, I don't know. I mean he's an adult now, and he still smokes. I just didn't want somebody saying, well, you didn't watch him. So he smoked out on the deck. And we sat and played poker. We just played with loose change, and we all had good fun. They treat you the way you treat them. I never had no lip from any of them. I kinda miss that. I don't know, I can't think of much of anything else. I mean, life goes on. It's just one of those things you have to do.

I'll call you in a day or two, so if you think of anything you want to add or clarify you can do that then.

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